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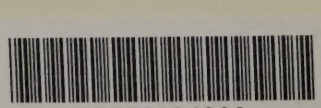
Select Committee on the Assisted Dying for the Terminally Ill Bill

Assisted Dying for the Terminally Ill Bill [HL]

Volume III: Evidence—Individual Submissions

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HL Paper 86-III


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HOUSE OF LORDS

Select Committee on the Assisted Dying for the Terminally Ill Bill

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Volume III: Evidence—Individual Submissions

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HL Paper 86-III

ASSISTED DYING FOR THE TERMINALLY ILL BILL [HL]

SELECTED INDIVIDUAL SUBMISSIONS

The select committee received over 14,000 personal letters or other submissions from individuals in regard to the Assisted Dying for the Terminally Ill Bill. A brief analysis of these is given in Paragraphs 230-231 of HL Paper 86-I. This volume reproduces a small selection.

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Written Evidence

Memorandum by Professor Margaret Battin of Utah University, USA

MY BACKGROUND

I am Distinguished Professor of the Department of Philosophy and Adjunct Professor of Internal Medicine at the University of Utah in the USA. I have authored, edited, or co-edited at least a dozen books, among them a study of philosophical issues in suicide, a collection on age-rationing of medical care, a study of ethical issues in organized religion entitled *Ethics in the Sanctuary*, and *The Least Worst Death: Essays in Bioethics on the End of Life*. I have been engaged in research on end-of-life medical decisions in the Netherlands and Oregon. In 2000, I was a co-recipient of the Rosenblatt Prize, the University of Utah's most prestigious award.

SUMMARY OF SUBMISSION

1. *Palliative care and physician-assisted death*
   - The question "What would you rather have, access to palliative care and hospice, or access to physician-assisted death?" presents a false dichotomy and does not fully address the needs, wishes, and realities of dying patients.
   - Opponents contend that legalization would undermine progress that has been made in improving palliative care and hospice. However there is dramatic evidence in both Oregon and the Netherlands that palliative care improves with the legalization of physician aid-in-dying.

2. *The argument over physician-assisted death*
   - In the past, debates about risks and benefits of legalization have been based on theory and conjecture. We now have empirical knowledge and data about the effects of legalization in Oregon, and the Netherlands.
   - Opponents' presentation of data from Oregon and from the Netherlands is incomplete and frequently filled with factual inaccuracies and distortions.
   - Many of the value-assumptions of those who oppose legislation are based in religious views. While religious commitments are to be respected, they should not be permitted to control social policy.

3. *Addressing (and defeating) opposing arguments*
   - Patient autonomy is actualized in physician-assisted dying.
   - Studies of physician practice show a measurable incidence of physician-assisted death whether legal or not.
   - In the vast majority of cases, assisted death is provided in the last week or last day before death would otherwise have occurred.
   - Already accepted methods of negotiating death offer the patient few protections or safeguards.
   - The comfort provided by having the possibility of an easier death, even if one never actually uses it, can be enormous.
   - Society allows patients to make other end-of-life decisions—like refusing further treatment—without assuming that the patient is depressed.
   - No proposed statute for legalization would permit providing physician-assisted death without careful safeguards.
   - There is no evidence of sustained substantive abuse in either Oregon or the Netherlands.
   - There is a deep compatibility of excellent palliative care and physician-assisted death.

4. *The philosophical debate over legalizing physician-assisted suicide*
   - "Liberty" and "mercy" are fundamental principles of our society and are central to the case for legalization.
   - There is an ethical requirement for physicians to try to respond to autonomous requests from patients, and to not abandon patients.

— The opposition claims killing is intrinsically wrong but accepts killing in self-defense, war and capital punishment.

— The opposition cannot show that the principles or liberty and freedom, basic to an open, liberal, democratic society, should be overridden.

5. *Conclusion*

— Physician-assisted death should be one of the last-resort options available to a patient who is facing a hard death. Different people who are dying have very different ideas and values about what would be, for them, the least worst death, and for some, an easier death with the assistance of their physician is vastly preferable to being allowed to die of their disease.

— An open practice is better for patients, families and society.

Below I outline more extensively, my arguments and reasoning

1. *Palliative care and physician-assisted death*

1.1 There is a growing consensus that palliative care is a core part of treatment to be offered to all severely ill patients who are potentially facing death[1]. However, challenging questions remain about how broad a range of choice patients may have in this process and about what limitations should be placed on the physician's obligation to address patient suffering. Physician-assisted death has long been the focal point of ethical and political debate—a "hot-button", divisive issue in a domain where there is otherwise considerable consensus.

1.2 If the question were, "What would you rather have, access to palliative care and hospice, or access to physician-assisted death?" most people would choose palliative care and hospice. Palliative care should be part of standard care for all severely ill patients, even those who are continuing active disease-directed treatment, and hospice should be the standard of care for all those who understand and accept that they are dying. I agree that access to physician-assisted death should not undermine processes and programs that promote comprehensive palliative care for patients and their families.

1.3 However, to frame this question in this way presents a false dichotomy: it serves the purpose of opposing access to physician-assisted death without fully addressing the needs, wishes, and realities of dying patients. I therefore prefer a more inclusive question: "What would you prefer, access to excellent palliative care and hospice by themselves, or access to excellent hospice and palliative care plus legal access to a physician-assisted death as a last resort if your suffering becomes intolerable?"

1.4 Both proponents and opponents of legalization of physician-assisted death can join together in support of improving access to and delivery of comprehensive palliative care for all severely ill patients. Both sides can also acknowledge and bemoan inadequacies in access to and delivery of health care services in general in the United States (and I therefore presume the UK), as well as end-of-life care in particular.[2]

1.5 However, as a proponent of legalization, I part company with opponents in my belief that it is not fair or justified to hold the question of legal access to physician-assisted death hostage to await the solution of these inadequacies.

1.6 Opponents of legalization contend that legalization of physician-assisted death-which they routinely demonize by using the term "physician-assisted suicide"—would undermine progress that has been made in improving palliative care and hospice. Not only is this not true, but there is dramatic evidence in both Oregon and the Netherlands that palliative care improves with the legalization of physician aid-in-dying.

2. *The argument over physician-assisted death*

2.1 In the past, debates about risks and benefits of legalization have been based on theory and conjecture. Even in the USA, the Supreme Court suggested when it addressed this issue in 1997 that "perhaps we should wait [on the question of legalization] until we know more."[3; 4] Fortunately, we now have five years of empirical knowledge about the effects of legalization in Oregon,[5-7] as well even more detailed empirical data from the Netherlands at various points over a 16 year period. Both of these data sets support the claim that a legal process can be contained; that little or no substantive abuse occurs. None is reported in Oregon, and much, much less than has been claimed in the Netherlands. Legislation is also associated with critical improvements in palliative care and hospice in both settings.[8]

2.2 Although "suicide" can be heroic and/or rational depending on setting philosophical and orientation[9; 10; 11], suicide in much writing is conflated with mental illness, and suggests the self-destruction of the person who is not thinking clearly or acting rationally. In most cases where a patient requests a physician-assisted death, however, distortion by depression or other forms of mental illness-although it must always be considered—is not a factor. We also know from studies in Oregon and the Netherlands that patients who choose this option

are generally acting out of a need for self-preservation because of being destroyed physically and deprived of meaning existentially by their illness and impending death.[12; 13]

2.3 I disagree with many of the value-assumptions of those who oppose legislation, as well as their construction of the arguments opposing physician-assisted death, and especially with their reliance on utterly unfounded "slippery-slope" arguments that predict wholesale abuse if assisted dying legislation should come into force. Whilst I welcome the discussion, I do not believe that essentially religious values should control social policy.

2.4 Furthermore, opponents' presentation of data from Oregon and from the Netherlands is quite incomplete, and frequently filled with factual inaccuracies and distortions that provide a false empirical cover for their moral opposition to the legal practice of physician-assisted death. For example, a recent book began with an accurate statement: "The debate over assisted suicide has helped to stimulate the medical community, and palliative care specialists in particular, into accepting the challenge to provide better care at the end of life . . ." But it then went onto say: "What we have learned from the Netherlands, Australia, and Oregon, however, indicates that legal sanction for assisted suicide and euthanasia complicates, distracts and interferes with the effort to improve end-of-life care."[14]. On the basis of existing empirical studies, this is flatly wrong. Unfortunately it is doubtful that more data will ever really settle a debate that is often more moral and philosophical than empirical.[15].

3. Addressing (and Defeating) Opposing Arguments

Below I present (*in italics*) and respond to some of the main arguments used to oppose physician-assisted dying:

3.1 *Physician-assisted suicide means that physicians will have control over who lives, who dies.* However, patient autonomy is actualized in physician-assisted dying and physicians are reluctant participants out of a sense of commitment to their patients.

3.2 *If physician-assisted suicide is not legalized, it will go away.* Nothing could be further from the truth; every study of physician practice in the United States, as well as studies in other countries, show a measurable, fairly consistent incidence of physician-assisted death (whether assisted suicide or voluntary active euthanasia) whether legal or not.[16; 17] The more realistically posed question about legalization must therefore focus on comparing an open, legally regulated practice versus a secret practice.

3.3 *Physician-assisted dying is an issue of life vs. death.* This too is in error. A Physician who assists in the death of a terminally ill patient does not make the difference between death and indefinitely continuing life, but between death now and death a little later, but in a much worse way. The amount of life usually forgone is typically quite small. Data from the Netherlands, where these practices are legal, show that patients choose to forgo on average only about 3.4 weeks of life, and that in the vast majority of cases, assisted death is provided in the last week or last day before death would otherwise have occurred.[18; 19]

3.4 *Already-accepted methods of negotiating death, including withholding and withdrawal of treatment, high dose opioids for the treatment of severe terminal pain or shortness of breath, and terminal sedation are less subject to abuse.* Although there is wide ethical and legal acceptance of these practices even when they bring about the death of the patient, few protections are systematically available to the patient here.[20] There are no safeguards for patient voluntariness, transparency of action, or protection from pressures from family, clinicians, or health-care institutions such as those being proposed if physician-assisted death is legalized.

3.5 B*ecause few patients would make use of physician-assisted death, it is not important.* Two things are wrong with this claim: the assumption that if only a small proportion of dying people actually use physician-assisted death, it isn't important to others who are facing death; and the quite callous view that dismisses the rights and interests of those who would use it. The comfort provided by having the possibility of an earlier, easier death, even if one never actually uses it, can be enormous. For those who do use it, dying in a way of their own choice can be of central importance in the meaning of their now-completed lives.

3.6 *Depression is ubiquitous in the seriously ill, so such patients cannot make these decisions rationally.* Clinical data shows no distorted thinking from depression in patients who actually receive physician-assisted death.[21; 13] Depression assessment can be tricky in any end-of-life decision[22], but I would argue for an open practice with careful clinical evaluation for all practices, legal or not, that might end in a patient's death, rather than outright prohibition. Society now allows patients to make other end-of-life decisions-like refusing further treatment or quitting dialysis-which will also result in death, without assuming that the patient who makes such a choice is therefore depressed.

3.7 *There is something wrong with patients who seek this kind of control.* All patients, like all people, eventually die; "mastering death" is not in question. What patients sometimes seek is control over the way in which their (inevitable) deaths come about. As a society, we admire people who assume responsibility for the way they live their lives in other areas; there is no reason not to do so as they live the very last portions of their lives.

3.8 *Kevorkian is an example of what legalizing PAS would bring*[23]. Neither Oregon's Death With Dignity statute nor any proposed statute for legalization in the United States (and I therefore presume the UK) would permit providing physician-assisted death for terminal patients without careful safeguards. Such safeguards would include repeated oral and written requests, waiting periods, confirmation of the diagnosis of terminality, and provision for psychiatric evaluation if uncertainty about voluntariness. Many of Dr Kevorkian's cases would not meet these safeguards. Kevorkian, in fact, is an example of the kind of protest that can happen when physician assistance in dying isn't clearly legal.

3.9 *In Oregon and in the Netherlands, legalization has been accompanied by real abuse, and patients are sometimes railroaded into death.* There is no evidence of sustained substantive abuse in either Oregon or the Netherlands, and the notorious "1,000" cases said to represent serious abuse in the Netherlands has been proven, on close inspection, not to do so.[24] To the contrary, legalization has been associated with marked improvements in palliative and end of life care in both settings.

3.10 *Good palliative/hospice care is incompatible with physician-assisted death.* Of all the misconceptions and errors perpetrated by opponents of assisted dying, this is perhaps most damaging in its departure from the truth. There is a deep compatibility of excellent palliative care and physician-assisted death as a last resort. The majority of patients in Oregon who chose assisted death under the Death with Dignity Act are enrolled in hospice programs, and the majority of Oregon hospices have chosen to continue to care for those who are considering this choice. In addition, the Netherlands now has some 129 inpatient hospices, plus 24-hour pain-control hotlines providing immediate advice for physicians. In the Netherlands, better palliative care has been very much a goal of medical policy[25].

4. The Philosophical Debate Over Legalizing Physician-assisted Suicide

Principal arguments for legalization of physician-assisted death	*Principal arguments against legalization of physician-assisted death*
— Patient autonomy/liberty	— The wrongness of killing
— Mercy: the relief of pain and suffering	— The integrity of the physician
— Nonabandonment: commitment to patient and family	— The risk of abuse (the slippery-slope argument)

4.1 Two philosophical concerns are central to the case for legalization: liberty-variously called freedom, self-determination, or autonomy-and mercy, the right to seek to be free from pain and suffering.

4.2 These two basic points—liberty and mercy, often phrased as the right to live one's life as one sees fit (subject to the constraint that one does not harm others) and the right to seek to be free from pain and suffering, are fundamental principles of the society in which we live: no one should be deprived of liberty, or forced to suffer, without adequate cause. The burden of proof lies with those who object to these two cardinal points: they must show either that some still more basic principle trumps these claims, or that honoring them would have seriously negative consequences.

4.3 The third principle, non-abandonment, more precisely a norm of practice for physicians, follows from the first two. There is an ethical requirement for physicians to try to respond to autonomous requests from their patients, especially when those requests revolve around extremes of suffering in those who are otherwise dying.

4.4 Autonomy focuses on the values and wishes of the particular patient who finds himself in an untenable situation. But assistance in dying, if it is also to involve physicians, cannot be solely a matter of patient choice. The nature of the patient's suffering and why it is intolerable to the patient must also be understood by the physician, who then is obligated to try to respond as a matter of mercy and of fulfilling his commitment not to abandon. Thus autonomy and mercy go hand in hand: for the physician to offer assistance in dying, it must be both the patient's choice and it must help that patient avoid suffering that is intolerable, or about to be so.

4.5 The opposition argument first claims that killing is intrinsically wrong. Yet in a culture which accepts killing in self-defense, in war, and (more controversially for the USA) in capital punishment, it is hard to see why assisting a person who earnestly wants help in ending his or her own life, where that person's illness is terminal and life is ending anyway, should be prohibited.

4.6 The opposition also tries to show that the consequences of legalizing physician-assisted dying would be bad: this is the point of slippery-slope claims about the potential for corrupting physicians and that abuse is widespread in the Netherlands and perhaps Oregon. Yet there is no evidence for these claims, and substantial evidence to the contrary. The opposition must show that the principles of liberty and freedom from suffering that are basic to an open, liberal and democratic society should be overridden. But this they cannot do. The burden of proof lies with opponents, but is, I think, doomed to failure.

5. Conclusion

I clearly believe that physician-assisted death should be one—not the only one, but one—of the last-resort options available to a patient who is facing a hard death. I agree that these options should also include high dose pain medication if needed, stopping life sustaining therapy, voluntarily stopping eating and drinking, and terminal sedation, but I also believe that physician-assisted death should be among them. Clinical assessments for all these options are more similar than different, as are the risks and benefits.

The practice of physician-assisted death should be safe, legal and relatively rare[26]. Most important, end of life options should be a matter of open choice for patients, since different people who are dying have very different ideas and values about what would be, for them, the least worst death[11]. I believe that an open practice that includes frank conversation, a broad look for alternatives, second opinions by those with expertise in palliative care, and clear documentation is better for patients, families and society than the current secret practice. The current secret practice of physician-assisted death discourages open conversation, often has patients and families acting on their own, has no documentation, and encourages altering the truth about actions and motivations.

I hope that during your enquiry you will look at all the arguments and data, and not be swayed by distortions about risks or by subtly concealed personal religious arguments that are not appropriately part of public policy. To know that we can be granted the option (whether we would actually use it or not) of facing our deaths in the way most in keeping with our own deepest values is a matter of enormous potential importance to all people—since we all must die. Most dying people would not choose an assisted death. However, for those that would choose this way of dying, the freedom to do so is of paramount importance. The deeper the understanding we all have of the underlying issues and the importance of options at the end of life, the better we will together be able to develop sensible policies that are both responsive to and protective of, terminally ill patients and their families.

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July 2004

Memorandum by Professor dr Bert Broeckaert

Author

1. Prof dr Bert Broeckaert is a specialist in end of life ethics and comparative ethics. He is Director of the Interdisciplinary Centre for Religious Studies (K U Leuven, Belgium), member of the Belgian National Bioethics Advisory Commission and ethical advisor of the Flemish Palliative Care Federation (that unites all palliative care services in Flanders). He was core group member of the European Pallium project (Palliative Care Ethics, EU, 1998–2001), was invited speaker at the 8th (The Hague 2003) and 9th (Aachen 2005) Congress of the European Association for Palliative Care (EAPC) and is member of the EAPC expert working group on prognostic factors in advanced cancer patients.

Limited Scope

2. As ethical advisor of the Flemish Palliative Care Federation Bert Broeckaert was the author of the position papers of the Federation on the Belgian euthanasia bill (infra, 9). These position papers, that played an important role in the Belgian euthanasia debate, were not a plea for (or against) euthanasia or a plea for (or against) a euthanasia law. Written from a palliative care perspective and in a situation where euthanasia was very likely about to be legalised or regulated (as was the case in Belgium), these papers focused on a number of problematic aspects of the bill and contained some specific proposals and amendments. Though the contribution presented here is strictly an individual one, its content is not any different from the views set forth in the position papers of the Flemish Palliative Care Federation. Similarly, the fact that in this text only a limited number of criticisms and suggestions are made does not imply that I agree (or disagree) with the different aspects of the Assisted Dying for the Terminally Ill Bill not discussed here nor that I believe (or deny) that in the UK or elsewhere a euthanasia law or this euthanasia law is preferable or necessary.

Belgian Euthanasia Debate and Law

3. Though much can be learned from the long and well-documented Dutch experience with euthanasia and euthanasia regulations, it would be a mistake to overconcentrate on the Dutch example. One should be fully aware of the fact that in The Netherlands palliative care became prominent at a time in which the euthanasia debate had in fact already been settled. The result of this is that organised palliative care and palliative care

issues played only a very limited role in the Dutch debate and that palliative care is not explicitly mentioned in the Dutch euthanasia regulations and law. In Belgium (and this would, with the exception of The Netherlands, be the case for any other European country) the development of palliative care preceded the euthanasia debate and the euthanasia regulations resulting from it. As a result of this, Belgian (especially Flemish) organised palliative care could play and did play a very active role in the Belgian euthanasia debate, palliative care and the relationship palliative care/euthanasia was one of the items that in the debate was discussed most often and most thoroughly, palliative care is explicitly given a place in the Belgian euthanasia law and the euthanasia law itself was linked to a palliative care law. For this author (and for the Flemish Palliative Care Federation) it is essential to put euthanasia requests and euthansia regulations in a broader perspective of end of life care. This broader perspective could be missed when only the very specific and in fact unique Dutch history and approach would be singled out for closer inspection.

Dialogue and Interaction . . .

4. People do not request euthanasia out of some morbid death wish, or because they have always wanted so much to die, but rather because at a certain moment in the process of their illness the suffering becomes too much to bear. Various factors can play a decisive role in this, often in combination: fear of what is to come, respiratory difficulties, physical pain, loss of control over bodily functions, increasing weakness and dependence on others, etc. A request for euthanasia always has something to do with an existing or expected decline in one's quality of life, is always the result of the patient's physical, psycho-social and/or spiritual suffering. It is therefore the responsibility of the caregiver who receives a euthanasia request to get through successive open and in-depth discussions (Art 3, §2, 2° of the Belgian law on euthanasia) a fair idea of the reasons behind the patient's desire to end his/her life: what is it exactly that makes the patient's life no longer bearable? This crucial idea of dialogue and interaction (which is much more than "informing" and "being informed") is not sufficiently present in the Assisted Dying for the Terminally Ill Bill.

. . . in a Context of End of Life Care

5. Given the delicate, irreversible and radical nature of euthanasia, it is of the utmost importance that euthanasia is only performed when it is a matter of suffering "that cannot be alleviated" (Art 3, §1 of the Belgian euthanasia law), and a situation "for which there is no other reasonable solution" (Art 3, §2, 1° of the Belgian euthanasia law)—an idea which is not clearly present in the Assisted Dying for the Terminally Ill Bill. Before considering euthanasia, the caregiver and the patient must find out whether a "normal", less controversial and less problematic medical treatment might not be able to alleviate the physical, psycho-social and/or spiritual suffering which has been found to lie at the origin of the request for assisted dying. For example, when a patient requests euthanasia because the physical pain is no longer tolerable, checking and optimising pain therapy would be a mandatory first step. A request to end one's life, even if it is still vague, must always give rise to an evaluation and, if necessary and possible, an adjustment of the care regime. What might be done to gear the care even more to the needs of the patient? Is it really impossible to alleviate the patient's suffering? Or have I, as a caregiver, simply reached the limits of my own competence and is specialised advice therefore required?

Interdisciplinarity

6. A physician who receives a request for euthanasia can never act alone when caring for this patient or when making a decision about honouring the euthanasia request. Dealing with a euthanasia request in a responsible manner always involves an interdisciplinary approach, for, on the one hand, there are many diverse and complex motives which can underlie a request to end one's life and which can only be adequately detected when different perspectives are put together. It is clear, on the other hand, that specialised input from various disciplines is often necessary in order to alleviate the patient's suffering.

The Voice of the Nurses

7. Nurses play a crucial role in end of life care. They are often very close to their patients, both literally and figuratively. Their everyday caring involvement with the dying patient teaches them a great deal about the patient's fears, questions and needs. They are in the best position to notice any small changes in the patient's condition which might have an enormous influence on the patient's quality of life. For this reason, the Flemish Palliative Care Federation believed it to be essential that a physician should have prior consultation with the nursing team before granting any request for euthanasia, a requirement that eventually was included in the Belgian euthanasia law (Art 3, §2, 4°) (and is regrettably absent in the Assisted Dying for the Terminally Ill Bill).

A Palliative Filter

8. Given the important role played by interdisciplinarity and specialised advice, it is strongly recommended that the local palliative team is consulted when a physician is confronted with an euthanasia request. In this way, the tragedies associated with pseudo choices, which have more to do with a lack of good palliative care than with an express wish to end one's life, can be prevented, thus making euthanasia a genuine option of last resort. It remains a pity that the suggestion of the Flemish Palliative Care Federation to include within the euthanasia procedure a prior palliative consultation with the palliative team from one's own institution or from the local palliative network (the so-called palliative filter), though this idea received the support of the Belgian Order of Physicians, was unanimously endorsed by the Commission for Public Health of the House of Representatives and in practice has become widely accepted, was finally not incorporated in the Belgian euthanasia law. It is indeed essential that the option of palliative care is seriously discussed with a specialist in palliative care (Assisted Dying for the Terminally Ill Bill 3(1)). It is essential too, however, that this consultation with a specialist in palliative care takes place *at the beginning* of the euthanasia procedure, as soon as the physician hears or even suspects that his patient is about to make a euthanasia request. Alternatives that are given late are no real alternatives anymore. It is psychologically and medically indefensible only after both physician and patient have taken the hard decision to go for euthanasia, to come with possible alternatives. Therefore the palliative consultation provided should move to an earlier stage of the euthanasia procedure. Given first of all the fact that this consultation not only should enable the patient but *also the attending physician* to make an informed decision and maybe find an acceptable and less drastic alternative and secondly the fact that information on palliative care alternatives (Assisted Dying for the Terminally Ill Bill 2(2)(iv)) can only be seriously given by the attending physician (whose knowledge of and experience in palliative care in most cases would be very limited) *after* he or she has consulted with a palliative care specialist, this palliative care consultation should also and first of all involve the attending physician and should chronologically be situated before 2(2)(iv).

Conclusion

9. A legalisation or regulation of euthanasia is highly problematic when an effective palliative filter is not included in the euthanasia procedure and when at the same time (and this is even more important) the government does not do everything possible to drastically increase the availability of good palliative care. A lot of euthanasia requests are in fact cries for help, camouflaging a lack of palliative care. Adequate palliative care can significantly improve the quality of life of terminally ill patients and thus often really helps, even when patients had explicitly asked for euthanasia before. One can discuss whether or not euthanasia should be legalised or regulated, but regulating euthanasia without placing it in a wider context of end of life care opens the door for tragic and uninformed pseudo-choices.

Further Reading

10. For an overview of the texts of the Flemish Palliative Care Federation I refer to B Broeckaert & R Janssens, *Palliative Care and Euthanasia: Belgian and Dutch Perspectives*, in *Ethical Perspectives* 9/2–3 (2002) 156–175. In the same thematic issue seven more articles on euthanasia in the Low Countries and the English translation of the Belgian and Dutch euthanasia law are offered. For a discussion of the genesis of the Belgian euthanasia law, see B Broeckaert, *Belgium: Towards a Legal Recognition of Euthanasia, in European Journal of Health Law* 8 (2001) 95–107.

1 September 2004

Letter from the Right Reverend Christopher Budd, Bishop of Plymouth

As I read it the above Bill seeks to:

— legalise assisted suicide within certain conditions; and

— make Advanced Directives legally binding in the UK.

I would like to make the following comments:

General comments

I hope Parliament will realise that should it go down this road (assisted suicide) it will change profoundly the ethos of health care in this country. Medical professionals are called to promote good health and to exercise

their special skills on behalf of life. The abortion situation has already introduced into one section of medicine a "corrupting ideology" and we seem to be standing on the threshold of introducing another. One can reasonably anticipate the gradual corruption of the total ethos of the medical profession.

It is easy to mock the "slippery slope" type of argument as "scare mongering", but the 1967 Abortion Act has to be a cautionary tale. Life in the womb is not only unsafe because of naturally occurring risks but, is even more unsafe because of human intervention often disguised mistakenly as concern for others. A society that does away with its young life on the scale we do has no real commitment to its future.

To destroy life at the other end of human existence can be reasonably expected to have the same corrupting effect on our society. The real test of the moral quality of a society is the way it treats its most vulnerable members. On that scale our society is scoring badly and is even wanting to achieve a worse score!

Specific comments

— The medical profession is called to care, treat and heal where possible. It can never be the purpose of this noble profession to kill. That principle must be upheld in law if our civilisation is to thrive.

  If someone in the grip of a life-threatening illness and suffering great pain (physical, psychological or spiritual), requests someone else to kill them, the response should not be the carrying out of the request but the providing of palliative care in its broadest sense. There is no obligation on the medical profession to keep someone alive as long as technically possible. There is an obligation to offer a patient whatever help current medical resources allow, even if that help is palliative rather than curative. There is never an obligation to continue futile or over-burdensome treatment. There is an obligation to provide basic care for any dying person, even if it is merely at the level of holding someone's hand or keeping them company, Basic care must normally include hydration and feeding where this is possible.

  (I have a suspicion that this Bill is an attempt to justify retrospectively the Bland judgement. Those promoting it should be honest about this. In the Tony Bland judgement the courts endorsed an instance of intentional killing. One could be excused in seeing here the onset of an undesirable trend).

  The request from someone to be killed should elicit from those standing around both empathy and care. It is quite often a cry for help to make sense of what is happening to them. What is happening is that death's challenge is being experienced in a very acute fashion and that needs addressing. The spiritual poverty of much of our culture is manifest in this ill-conceived Bill.

— The problem with Advanced Directives is that they are out of date as soon as they are signed. Medical treatment whether during life or at the end of life is a partnership between patient, family, legitimately concerned others and medical professionals. Legally enforceable Advance Directives will reduce medical professionals to technicians and exclude both family and others from any relevant input. Legally enforceable Advanced Directives will be the triumph of extreme individualism. Such a move is not in the public interest.

  General directives about the nature of ones future care could be both acceptable and useful. Specific Advanced Directives would almost certainly be out of date by the time they are invoked.

  I ask parliament not to demean or shackle our medical professionals by giving these so-called "living wills" force of law.

Final thought

Personal choice as the overriding value seems to underlie the thinking behind this Bill. Personal choice cannot be unbridled and will always be subject to moral boundaries. When it comes to issues of life and death (even if it is ones own) those boundaries need to be clear. They will always touch the public good and will either support or corrupt the ethos of trust that must exist if we are to maintain a trustworthy medical profession.

As you realise from what I have written I consider this proposed Bill to be ill conceived and I recommend very strongly that in the name of humanity it should be abandoned.

23 August 2004

Memorandum by Dr Jane Campbell, Chair of Social Care Institute for Excellence (SCIE) and Commissioner, Disability Rights Commission (DRC)

Introduction: Supported-Living Values versus the Dying Process

1. Over the last several years the campaign for euthanasia has gained momentum. Individuals talk of wanting not to die in pain, with indignity and the loss of control of bodily functions. They talk of being a burden on friends and family. Severe incapacity or terminal illness has always been a taboo subject in our society. The general population deeply fear losing their mental or physical faculties and feel the answer to that anxiety may well lie in euthanasia legislation. It is my view that before we consider regulating the dying process we need to deal with society's deeply held prejudice about the quality of life of people with a so-called terminal illness. For it is my belief, that until we introduce supported living values into the psyche of our society, we can never have a balanced debate on euthanasia legislation. For this reason the majority of disabled people in the UK disabled people's movement oppose this Bill.

2. In 1999, a global summit of disabled people met in Washington DC, to discuss the situation and concerns of people who require human support to live.[1] The conference concluded with a declaration of principles of interdependent living.[2] The first of these principles states:

> ". . . that all human life has value and that every human being should have meaningful options to live with dignity and respect."

3. If we accept that all human life has value, it follows that we should strive to value the individual human life. Regrettably, in current society, some lives are deemed more valuable than others. Disabled people who live with a terminal illness tend not to be seen as leading meaningful lives as I will demonstrate. Drawing upon my own experience and the evidence I have gathered from working and campaigning within the disabled people's movement over the past 25 years, I will argue that severe incapacity is typically perceived to be an inferior state of being. In such circumstances, legalising euthanasia or as Lord Joffe's Bill calls it "assisted dying" risks the lives of people with no wish to die. My evidence is not centred on a moral or ethical position on the right to live or die. What I wish to discuss here is the impossibility in the present climate of opinion of ensuring that terminally ill lives will not be put at risk.

My Personal Concerns about a Growing Euthanasia Culture

4. When I was born, my mother was advised to take me home and enjoy me as I would die within a year. As can happen with the prognosis of terminal conditions the doctors got it wrong. Although I was frequently unwell, mostly with life-threatening chest infections, I was treated with life-saving antibiotics and ventilation and thrived in this positive medical environment. Happily, some 40 years later, I remain very much alive.

5. But I have noticed a change over the last two or three years, especially in the aftermath of the high-profile Diane Pretty case, which has influenced public opinion, including that of some medical professionals, to generalise Pretty's situation to all patients with diagnosed terminal conditions. Devastating is not too strong a word to describe an experience I had in January 2003, when I was admitted to hospital with severe pneumonia in both lungs and required emergency treatment.

6. The consultant who was treating me commented: "You are very ill. If you go into respiratory failure I am assuming that you do not want to be resuscitated with a ventilator." I was a taken aback by this and said, "Well, why?" He replied that the chances of weaning me off the ventilator would be very remote—"And you wouldn't want to live on a ventilator." When I said that meant I would die and of course I want to be ventilated, he looked (I thought) puzzled but appeared to let the matter drop.

7. The next day I was in intensive care when another, more senior, consultant repeated the same message: "If you go into respiratory failure—and this looks likely—then I am sure you won't want to be anywhere near a ventilator." Again I protested but by now I was getting very scared. My husband tore home, grabbed a photograph of me in my doctoral graduation robes, and returned to the hospital shouting to the doctors: "This is my wife, not what you think she is. She has everything to live for. You do everything for her just as you would for anybody in this situation." Such extreme measures helped bring about a change of mind and I have lived to tell the story, albeit I kept myself awake for the next 48 hours, fearful that if I went to sleep I'd never wake up.

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[1] "Global Perspectives on Independent Living for the Next Millenium", an international summit conference on independent living, Washington, DC, 21–25 September 1999.

[2] The full list of principles, known as "The Washington Declaration" can be accessed on the Independent Living Research Utilization website: www.ilru.org/summit/index.htm

Does this Experience Speak for Others? Am I the Lone Voice?

8. In the UK, the Disability Rights Commission, Disability Awareness in Action and similar organisations are gathering evidence about assisted dying from disabled people and their families. These works in progress are demonstrating that decisions regarding life-saving treatment are often made in an environment of ignorance and discriminatory attitudes towards and about disabled people. In addition, society's obsession with image and the body beautiful reinforces negative stereotypes that disability is equal to a state worse than death. This personal submission of evidence for the Select Committee is not the place for comprehensive report and analysis on research within the disability community on this issue. However, I would like to quote a small number of individuals from within the disability community who perceive the proposed legislation to be a threat to their own safety and well-being, and/or think such legislation will exacerbate a culture of negativity around severe disability or illness.

9. *Michelline Mason*, Chief Executive of the Alliance for Inclusive Education, says that:

> "A message over the years clearly and firmly slipped into my unconscious, saying that people would prefer it if I died. It seems that since then I have spent nearly all my life desperately trying to prove that I should be alive, that I was not suffering (even when I was) [and] that I was not worthless, but indeed exceptionally worthwhile.[3]"

10. Michelline, diagnosed from birth with severe brittle bone disease, had the wherewithal to resist her social fate, but many severely incapacitated individuals are in danger of succumbing to the negativity that can lead to suicide, and these are among the very people with a diagnosed terminal illness that the Bill is targeting.

11. *Roy Webb*, Head of Policy, National Centre for Independent Living (NCIL), writes:

> "This [Assisted Dying] Bill adds to the negative images of disabled people by focusing on the pain and suffering that we sometimes experience. The Bill will, in my opinion, add to the general public view that if you are ill or disabled and certainly if you have a terminal illness, that your life is somehow inferior to that of other people. In fact, although I have [Multiple Sclerosis] and this is sometimes described as a terminal illness, this has never been any concern to me in my life . . . If [people with terminal illnesses] are getting the support they need and can live the life they choose, perhaps they will not feel the need to bring their lives to an end.[4]"

12. As members of the Select Committee will know, the Member's Bill on Assisted Dying was defeated last year largely on the grounds that it threatened the lives of disabled people. In response to this objection, the Bill has been re-drafted, narrowing its scope to the terminally ill. Roy's testimony highlights the fact that people with Multiple Sclerosis, Motor Neurone Disease, Altzheimer's Disease, Parkinson's Disease etc—in other words, the chief alleged beneficiaries of assisted suicide—do not make such easy distinctions between disability and terminal illness.

13. In 2000, Rachel Hurst, Director of Disability Awareness in Action (DAA), made the following plea on behalf of disabled people to the Bioethics community at their 5th World Congress:

> *It takes a particular sort of courage to rise above these negative impacts and have a faith in your own worth, or the worth of your disabled family member. It takes courage and a clear understanding that disability arises from the social barriers of attitude and environment to your impairment, not the impairment itself . . . Just as we all recognise that society needs the difference of women and people of different races and backgrounds, so society needs people with impairments.*[5]

Fear, Bias and Prejudice Against Terminal Illness

14. My own experience and that of others demonstrate the strength of negative beliefs about severe impairment prevalent in our society. The perception that disabled people with terminal conditions live flawed and unsustainable lives is one of these negative beliefs. The belief that death is preferable to severe impairment is another. It is difficult enough encountering these attitudes in day-to-day living. In the context of Assisted Dying it is more worrying that such beliefs are sometimes held by medical professionals who, let's face it, are ordinary people like the rest of us, subject to much the same social stereotypes.

15. In 1999 an 18 month old child, ("Baby C"), with Spinal Muscular Atrophy (SMA) was denied ventilation to help her through a chest infection. The decision was made on the basis that her "disability was too terrible to live a quality life". In addition she would need "total bodily care for the rest of her life" and this would be a "burden on state resources and family support"[6]. The family did not accept this decision and took the

[3] Personal communication.

[4] Personal communication.

[5] R Hurst, "Ethics and Disability, Celebrating Diversity", Paper to 5th World Congress on Bioethics, Solihull (UK), 2000.

[6] R Daw, "The Impact of the Human Rights Act on Disabled People", Report prepared for DRC & RNID, 2000.

hospital to Court. The Judge ruled for the hospital having received advice from a range of doctors, who all categorically stated that no one with this diagnosis could live beyond the age of two, and even if they did, their life would be little short of a living hell. Adults including myself can tell a very different story about living with SMA. The baby died as a result of being denied the health care offered routinely to non-disabled babies with severe chest problems. The view taken by the doctors in this case demonstrates the prevalent attitude in society towards terminal illness.

16. Seventeen years ago *Dr Ian Basnett*, a young doctor with everything to live for, was left quadriplegic following a sporting accident. He admits that before the accident,

> *". . . like many people, I had a terribly negative image of disability. When you suddenly become severely disabled you still have that viewpoint. Before I was disabled, I was working as a junior doctor. That brought me into contact with disabled people and I remember admitting a man with quadriplegia. My reaction was, 'how could anyone live like that?' "*[7]

17. The Disability Rights Commission (UK) is unanimous in its opposition to the passage of this Bill. Members of the Select Committee will also be aware of similar opposition by disabled people in other countries.[8] There is no disabled peoples' collective in the UK that seeks passage of this Bill.

18. Some individuals seeking the legalisation of Assisted Dying claim this is a human rights issue. I am not alone in repeatedly drawing attention to the fact that human rights are as much a social issue as they are a matter of personal autonomy and neither can be considered in isolation.

19. The Voluntary Euthanasia Society (VES) has reportedly described people with MS as being incurably ill, and those who wish to assist them to die as performing a supreme act of compassion. This view demonstrates the strength of such a negative medical model. We may feel it is a compassionate act to help someone end a life that is intolerable to them. The danger is the assumption that terminal illness alone, in this case the physical condition brought about by Multiple Sclerosis, is sufficient to explain the intolerable nature of life. This will be dependant upon many other factors, such as the home environment, physical barriers, the level of care and support available and access to other individuals living with the condition.

20. If I were to be denied my electric wheelchair, my adapted home, my accessible vehicle and my personal care assistants, I might conclude that my life was intolerable. With them I am able to enjoy a high-quality life.

21. Assisted Dying might be a viable alternative if good quality palliative and social care becomes available across the country. At present this kind of support is patchy at best. If someone chooses death in the absence of such support, their decision is likely to be influenced by this fact.

22. While the Assisted Dying Bill aims to address the needs of patients in the last stage of their lives, I am concerned about the underlying message of the Bill that death is the preferable solution for people severely incapacitated or in pain. Much the same message is communicated to older people who fear being a burden to others, and to terminally ill and disabled people with inadequate care packages. These views will be legitimised if the law is changed to concede that they might be better off dead.

23. I cannot accept the dangers that would attend assisted suicide in the current climate of opinion. Diane Pretty was a British disabled person who went to the European Court to fight for the legal right to be assisted by her husband to die. What alarmed me and confirmed my fears was the public and press response to her situation. Every newspaper supported the "mercy killing" of those with terminal impairments.

24. Assisted suicide is not an issue that can be resolved by experts alone. On the basis of press coverage of the Diane Pretty case, the public could be forgiven for believing that everyone with a substantial degree of disability will inevitably be deeply depressed and pre-occupied with thoughts of dying. It is significant that her campaign was never questioned in the media.

25. The consequences of legalising assisted dying are so dangerous that it cannot be considered until society is committed to assisted and supported living for the terminally ill. We must find ways to make life more comfortable for terminally ill people. We need to question the precise circumstances in which a person decides life is not worth living. To assume that the condition itself is the answer is to take too little account of the social, economic and personal contexts of illness.

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[7] I Basnett, "Will to live wins over the right to die", Observer (March 2002). Dr Basnett is now Deputy Director for Public Health, London Northeast NHS Regional Health Trust.

[8] Marilyn Golden, a policy analyst writing for the Disability Rights Education and Defense Fund (DREDF) in the USA summarises the case against the legalisation of assisted suicide in a succinct article available on the internet "Why Assisted Suicide Must Not Be Legalized": http://dredforg.assistedsuicide.html

26. Society seemed content to consign Mrs Pretty to the graveyard without looking more closely at the conditions leading to her wish to die. It is difficult to imagine such a simplistic scenario were Stephen Hawking to contemplate assisted suicide. Do we want Hawking to live because of his intelligence? Where do we draw the line?

27. Despite advances in modern medicine, we are all still fearful of serious illness and to any impairment that may reduce our capacity either physically or mentally. This includes even the aging process. Physical impairment flies in the face of our fixations with the "body beautiful" and looking and staying healthy. We spend millions on cosmetics and other remedies to perpetuate the myth of youth, while closing our eyes to social pressures that lead many people diagnosed with terminal illness to view death as the preferred option. I will feel safe only when society recognises the benefits of creating inclusive communities which embrace physical and mental diversity. Only then can we realistically consider the protective measures that need to be in place to ensure the viability of assisted dying legislation. When the debate and resources and framework are properly in place so that people can live with terminal illness, then we can consider options for people who persist in their desire to die.

28. We exacerbate a culture where death is considered an answer before we look at how society can incorporate and support such lives within the mainstream. I have been contacted by many disabled people who are still concerned about the potential consequences of this Bill—concerned that people with terminal illnesses may be put under pressure, overt or covert, to choose death rather than be a burden on relatives or the state. Physical and mental diversity are part of the human condition and most of us will have to face up to terminal illness before we die. We can face up to it or fear it. These are complex issues, and there is no easy consensus. The visibility of disabled people who are contributing to the welfare and productivity of society encourages able-bodied people to be more compassionate and constructively facilitative.

Conclusion: Valuing Life with Terminal Illness

29. If we agree that all human life is of equal value, then we must put our energy into ensuring that our environment and social systems support the inclusion of terminally ill people's lives. The campaign for this Bill is dangerous because it reinforces the current unequal value on life and leaves people like me feeling very unsafe.

30. The dangers of the current negative social response to terminal illness and disability not only threaten our chances of survival but also mark us out, sometimes fatally. I have already described my own close call with the view that I would be better off dead. It would appear my experience is far from isolated. My consultant neurologist told me that Diane Pretty's campaign made his job more difficult. It planted a seed of doubt in the minds of his patients that their lives will not be worth living once their conditions deteriorate and, *inter alia,* the most logical response to that would be assisted dying.

31. Instead of seriously considering all aspects of independent living, this legislation encourages assisted dying before we have fully addressed questions of interdependence and assisted living. Most of society sees people with terminal illnesses and disabilities as people who are flawed and without dignity. But we see ourselves as a vital and proud community, with values of our own that enhance our quality of life, values that could enhance life for all.

32. In addition to this written evidence, I am willing, and respectfully request permission of the Select Committee, to give an oral submission of evidence at an appropriate date.

"Jane Campbell's Authority to give Evidence"

I, Jane Campbell, am a Commissioner of the Disability Rights Commission (DRC).

I am the Chair of the Social Care Institute for Excellence (SCIE) which is an independent government-funded organisation dedicated to improving the quality of social care across England and Wales.

Before joining SCIE I was at the National Centre for Independent Living (NCIL) where I founded and Co-Directed the project for six years.

I was Chair of the British Council of Disabled People (BCODP) from 1991 to 1995 and saw the organisation through some of its most pioneering work in the field of independent living, civil rights, peer counseling and equal opportunities.

I have also held a number of honorary posts. The following is a select list:

1991–2001: Governor of National Institute for Social Work.

1995–2001: Parliamentary Representative of "Rights Now".

1991–date: Trustee of Disability Awareness in Action (DAA), an international public education initiative based on the 1983 UN World Programme of Action on Disability.

I have undertaken relevant research commissioned by, among others, the National Council for Voluntary Organisations, The Policy Studies Institute, Help the Aged and the Joseph Rowntree Fund.

I have undertaken relevant project management for: Camden Borough Council, Coventry City Council, The London Borough of Newham, Harrow Social Services, London Borough of Westminster Social Services and others.

In 2003 I briefed peers and made submissions on Lord Joffe's Patient Assisted Dying Bill.

I have books written on various subjects, including:

Disability Politics (with Mike Oliver), Routledge, 1996.

Good Guide to Disability Training, CCETSW, 1990.

Direct Routes to Independence, JRF, 1999.

My recent activities also include the following:

working with Dept of Health's Modernisation Agenda regarding NHS awareness with view to providing training and guidance.

advised Association of Social Service Directors on Independent Living Schemes and User Involvement.

assisting National Council for Voluntary Organisations via seminars and consultations with their work regarding the new Charity Commission Guidelines.

member of the Government's Technical Advisory Group on framing Government legislation for Social Service Direct Payments and Regulations and Guidance member of the General Social Care Council Advisory Group.

member of the Joint Implementation Group for SCIE.

member of the Ministerial Disability Advisory Group chaired by Maria Eagle MP, Under-Secretary of State for Disabled People.

Memorandum by Dr Colleen Cartwright and Associate Professor Malcolm Parker

PART 1

1(a) *The authors*

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1(b) *Background and experience*

We are members of a research team which has been investigating end-of-life issues for over 12 years, in Queensland and the Northern Territory (Australia) and in an on-going study with researchers in six European countries.

At the beginning of our work, the team gave a commitment to stay professionally neutral on the issue of assisted dying. All questionnaires and other study material have had to pass the scrutiny of a multi-disciplinary advisory committee whose members were known to hold strong viewpoints both in favour of and against assisted dying. This has given our work credibility in the field.

1(c) *Reason for this submission*

The research has convinced the authors of this submission that legislation is necessary to legitimise and regulate practices which occur reasonably frequently, currently in a clandestine and sometimes inexpert manner. We stress that this submission represents our personal views and not necessarily those of other members of the research team, nor of the institution in which we work.

If legislation is to be enacted to allow assisted dying for terminally ill patients, we believe that it should be as well-constructed as possible. Therefore, Part 2 of this submission addresses matters of content and structure in the Bill which we believe require amendment.

In Part 3 we present additional information which we respectfully request the Select Committee to consider.

Part 2—Drafting of the Legislation

2(a) *Purpose of the Bill*

We contend that it is unnecessary and potentially counter-productive for the issue of pain relief to be included in a Bill concerning assisted dying. There is general agreement in most developed countries, and in all mainstream religions, that adequate pain relief should be provided to patients, including those who are terminally ill. Indeed, some countries have legislated a "right to palliative care" (Peretti-Watel *et al*, 2003), which of course includes provision of pain relief medication. Other countries, including Australia, have legislated for the protection of health care staff who provide palliative care, including pain relief, to terminally ill patients if there is concern that such care may hasten the death of the patient.

Inclusion of the issue of pain relief in the purpose suggests that there is serious concern in the UK about inadequate relief of pain in terminal illness. If this is so, it requires urgent attention, both in professional education and in alerting the community to their right to receive adequate pain medication. Indeed, from a legal perspective, failure to provide adequate pain relief may be regarded as abuse or cruelty. However, we do not believe it belongs in this Bill; if it remains it may reinforce the notion that adequate pain relief is some form of euthanasia, which it clearly is not. In Australia and other parts of the world, this erroneous belief results in patients being left in pain at the end of their lives.

However, if the issue of pain relief remains in the Bill, then the word "adequate" should be inserted before "pain relief medication" in the first paragraph, and Section 15 should be amended, as follows:

- Rather than a terminally ill patient being "entitled to request and receive such medication . . .", it should be mandatory that such medication be provided, unless the patient refuses it.
- This section should also make it clear that the pain medication is to be given even if there is some risk that the patient's death will be hastened as a result.

2(b) *Section 1 Authorisation of dying*

Section 1(2) Definitions:

Assisted dying: While the words "providing the patient with the means to end the patient's life" is a clear definition of physician-assisted suicide, "ending the patient's life" (ie euthanasia) requires elaboration. For example, what practices are intended to be included in this definition? Is it only meant to cover lethal injections? Does it also include terminal sedation? Practices such as withholding or withdrawing life-sustaining futile medical treatment, or providing increased levels of needed pain relief medication, should be stated as being clearly excluded in this definition.

In addition, the words "if the patient is physically unable to do so" should be deleted from this section. Some patients, while physically capable, may not wish to take the action themselves, either because they fear that they will not do it correctly or because they regard the final relief of their suffering as part of their medical care, and wish that to be provided by a doctor. To restrict this service only to those who are not physically capable of committing suicide may increase the distress and suffering of other terminally ill patients who desire euthanasia.

Terminal illness: The included definition of "terminal illness" as ". . . likely to result in the patient's death within a few months at most" is too vague. What does "a few months" mean? We acknowledge that accurate prognosis of time to death is often extremely difficult, but contend that legislation requires specificity. In the Oregon legislation relating to physician-assisted suicide, terminal illness includes that the patient is expected to live for less than six months (Roscoe *et al*, 2001).

The Queensland *Powers of Attorney Act* (1998), which sets out the conditions under which life-sustaining treatment may be withheld or withdrawn, defines "terminal" as: "resulting in death—the patient can reasonably be expected to die within the next 12 months".

We recommend stipulating a period of six months.

2(c) *Section 2 Qualifying conditions*

Sections 2(d) and 3(d)

As the patient must decide that his suffering is unbearable, rather than the physician concluding this, clarity could be added by inserting additional words such as "from statements made by the patient" after the word "concluded". However, the definition of "unbearable suffering" in Section 1, which includes the words "which the patient finds so severe as to be unacceptable", may be sufficient.

2(d) *Section 4 Declaration made in advance*

Section 4.2

There is usually a cost involved in having a practising solicitor witness documents, which may prove prohibitive for some patients. In Australia, a JP or Commissioner for Declarations (whose services are free) may witness advance directives (although obviously these are for future health care provision and not for assisted dying).

Section 4.3(a) and Section 4.4(a)

Why should the patient have to "prove [?] his identity to the solicitor" (or other witness)? If the patient says who he is, and the attending physician knows the patient by that name, that should be adequate. After all, no one else is going to be assisted to die but the person making the statement.

Section 4.8

Although Section 4 pertains to a Declaration made in advance, and Section 4.8 states that the declaration shall remain in force for six months, there is no statement as to whether or not the declaration survives the patient's loss of competence, if that occurs within the six month period. This should be made explicit.

2(e) *Duties of physicians, and conscientious objection*

Sections 7(2) and 7(3).

This Section appears to be more "active" than would usually be required for a matter of conscience. Some physicians would find even referring the patient to someone who would assist him to die to be against their conscience. A better option would be that anyone who has a conscientious objection should not be obliged to participate but must not actively impede a patient accessing such assistance (once it is legally available). An official information service may be needed for people who want such assistance.

Also, while the physician may or may not know who "does not have such a conscientious objection", to make such referral obligatory (ie "he shall . . .") may put unfair pressure on the physician and may affect his future professional relationships.

2(f) *Section 8 Psychiatric referral*

Section 8.1

We commend the drafters of this Bill for not making a psychiatric referral compulsory for everyone requesting assistance to die. It is generally accepted (albeit not universally) that such requests can be entirely rational, given the patient's condition, quality of life and belief system. In addition, since psychiatric referral is not required for other, currently legal, actions which can result in the patient's death (eg withholding or withdrawing life-sustaining medical treatment), to make it mandatory for assisted dying would be discriminatory.

2(g) *Section 14 Monitoring commission and reporting requirements*

Section 14(2)(c)

The requirement that the lay member of the commission shall have "first hand knowledge or experience in caring for a person with a terminal illness" is problematic and may introduce bias, or at least an additional degree of complexity into the process. For example, if the person witnessed a distressing death of a loved one and, as a consequence, believes that assisted dying should be readily available to everyone who requests it, it may reduce the person's objectivity in assessing reported cases. Conversely, if a person cared for someone under distressing conditions for some time, and considers the patient to have been "very brave", the member's assessment may be that assisted dying was provided too easily. We accept that there should be a lay member on the commission but suggest dispensing with the qualifying conditions.

Section 14(4)

We commend the requirement that the commission "shall confirm to the attending physician concerned whether the qualifying conditions have been met as soon as reasonably possible ...". One of the authors of this submission (CC) spent some time in the Netherlands and interviewed physicians who had assisted patients to die, reported it as required and then waited more than 12 months before being told that they had met all requirements. This was a distinct disincentive to reporting.

2(h) *Schedule*

Declaration (by patient)

Statement number six requires one of two parts to be deleted. It would be better written as:

Please delete one of the following two statements:

— I have decided to inform my family of my decision.

— I have decided not to inform my family of my decision.

Signing the declaration

There is no provision for someone else to sign on behalf of a competent patient who may be physically unable to sign on his own behalf (eg because of a paralysing stroke which may have affected his body while leaving his mind clear). This should be added.

PART 3

We respectfully submit the following matters for the Committee's consideration:

1. *Terminal sedation*

A recent controversial addition to the assisted dying debate is the issue of terminal sedation and its relationship to euthanasia. Terminal sedation refers to the use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering, when other attempts at relief have failed. Usually this includes cessation of nutrition and hydration. The practice has been described as "slow euthanasia" (Billings & Block, 1996), with claims that it is ethically worse than assisting the patient to die, because it requires patients to linger for a few more days before they die (Singer, 2002), with the potential for further suffering. Gauthier (2001:48) argues that "with terminal sedation we are already legally permitting and practicing something closer to active euthanasia than is commonly recognised".

We acknowledge that some skilled palliative care physicians (eg Ashby, 2001) reject the contention that terminal sedation causes death because in such situations it is not usually possible to ascertain the relative causal contributions of disease, physiological and pharmacological factors to the timing of death. However, it appears that some health care professionals provide terminal sedation as a substitute for euthanasia, while others do not because they regard it as euthanasia, to which they are opposed, with the result that treatment for intractable terminal suffering may be underprescribed (Yanow, 2000).

2. *The need for openness, honesty and accountability*

The practice already occurs: There is widespread acknowledgement that assisted dying already occurs (Magnusson, 2002; Hoffenberg, 2000). Providing their responses are confidential, doctors and nurses acknowledge that they assist patients to die, including where it is not legal to do so (Douglas *et al*, 2001; Clarke *et al*, 2001).

Need for legal protection: Legalisation would protect doctors or nurses who already assist patients to die and who do so as professionally as possible, from criminal sanctions they now potentially face.

Need for open discussion/grieving: If assisted dying were legalised it could be discussed openly, allowing relatives and friends to also grieve openly. Because of the illegality, there can be traumatic psychological consequences for family members and others involved in assisting patients to die, including feelings of guilt and fear of detection. Singer (1994:148), describing a case of openly-conducted, active voluntary euthanasia in the Netherlands, notes that the patient

> had the best possible medical attention, right up to the moment of death. Her family could be with her, and even her priest. Nothing had to be furtive. There was no need to fear failure. No-one had to lie awake afterwards wondering if the police would knock.

Development of better procedures: Currently, assisted dying practices are totally unregulated. Decriminalisation would allow the development of better practices, including doctors working with pharmacists to develop a documented regimen of drug use producing least side-effects. When euthanasia is practised in secret, problems can, and do, occur, eg patients do not die after being given all available medication, leading in some cases to a family member having to "finish the job" by holding a pillow or some other object over the person's face. The resulting trauma is obvious and long-lasting (Magnusson, 2002).

Loss of respect for the law: Few cases of assisted dying come before the courts and those that do are treated leniently (Browne, 1990). If the law is not enforced, the public loses respect for it.

3. *Community's responsibility to terminally ill patients*

The success of science and medicine in dramatically reducing the number of deaths which occur from infectious diseases and from cardiovascular diseases have, in turn, created a situation where the majority of people will die from chronic illnesses. In many cases this will be via a long, drawn-out dying process that has the potential to produce great suffering, rob people of their independence, control and dignity and place great burdens on family and community resources.

We contend that the benefits conferred by medical progress bring with them a concomitant responsibility to provide an opportunity, through the medical profession and to agreed community standards, for people to manage their own dying in a manner which is consistent with their beliefs and values. This would include provision for assisted dying.

4. *Social justice*

Proponents of assisted dying argue that certain classes of people, eg those who are well-educated and in higher socio-economic groups, who know who to ask and how to ask, have access to assisted dying while the rest of the community does not (Fraser & Walters, 2000). Others claim that it is discriminatory that patients whose diseases make them dependent on technology can control their time of dying by requesting treatment be withheld or withdrawn, while patients who are not technology-dependent do not have this option and should therefore be assisted to die (Singer, 2002).

A related group of arguments include that there is no moral difference between withholding or withdrawing life support and providing assistance to die (Doyal & Doyal, 2001; Parker, 2001), or that there is no intrinsic moral difference between killing and letting die because both intention and outcome are the same (Hoffenberg, 2000). Young and Yeo (1989) argue that it is morally worse to prolong someone's suffering rather than kill them.

Some terminally ill patients are physically unable to commit suicide (despite that not being illegal) and are unable to have someone else assist them to die (because that is illegal), which means that they are effectively denied private options available to others (Fraser & Walters, 2000).

Vaux (1989:32) extends the social justice argument to patients whose deaths have been protracted by a range of interventions but who are then refused assistance at the end.

> Logically and emotionally, we cannot intervene at one phase and then be inactive at another, more painful phase. We cannot modify nature and then plead that nature must be allowed to run its unhindered course.

For the reasons given, we believe that passage of the Bill would alleviate a small but significant area of social injustice.

5. *We live in a democracy and the majority want it*

Many studies and opinion polls demonstrate that the majority of the community support the legalisation or practice of assisting terminally ill patients to die if that is what they want (Cartwright *et al,* 2002; Dickenson *et al*, 2002; Cohen, 2001). Perron (1995) argues that the minority may choose not to participate but should not deny the option to those who want it.

6. *If patients know assistance is available, they may delay taking action or not take up the option at all*

There are claims that some terminally ill people kill themselves before they really want to, for fear of losing control through hospitalisation or disability (Roy, 2002) and that legalising assisted dying would give patients peace of mind (Perron, 1995). Data from Oregon support the idea that some patients gain comfort just from having a lethal prescription available (Ganzini & Johnston, 1999).

In Summary: We submit that legislation is required to regulate and remove the secrecy from practices which already occur, to bring social justice to these practices and to meet society's obligations to terminally ill patients, Such legislation would almost certainly have wide community support.

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28 August 2004

Letter from Nessa Coyle, RN, PhD

I respectfully submit the attached papers[9] as evidence to the Committee in the House of Lords as its members review the Bill before the House on *Assisted Dying for the Terminally Ill.*

I am a nurse, who originally trained at St Bartholomew's Hospital in London, but have been working for the last 30-years at Memorial Sloan-Kettering Cancer Center in New York City. Since 1981, my clinical practice in our Pain and Palliative Care Service at Sloan-Kettering has focused on working with highly symptomatic advanced cancer patients and their families on both an inpatient and outpatient setting.

I am very familiar in working with terminally ill cancer patients who have expressed a desire for hastened death and the work that has been done by others suggesting that psychological and social factors have typically appeared to have more influence on the desire for death than physical symptoms. My own interaction with patients who had expressed a desire for hastened death made me realise that such an expression had many meanings and uses to the patient, and that such an expression was a form of communication and not necessarily a literal request.

In order to understand better what patients were asking for when they expressed a desire for hastened death, I recently undertook a small exploratory qualitative study with seven patients who were living with advanced cancer and had expressed a desire for hastened death. Through their own words—their narratives—of what it was like to live with advanced cancer I learned that the expression of desire for hastened death had many meanings and uses and was a tool of communication. It was a language that "ratcheted up the noise" and caused those who were involved in the patient's care to sit down, listen and "hear" what was being asked for and what was needed by the patient.

What struck me especially not only through the findings of this study but also through my ongoing work with these patients and families over many, many years, is their incredible vulnerability—their vulnerability to their environment and their vulnerability to the verbal and non-verbal communication of those around them—family, friends and staff.

2 September 2004

[9] Not printed, see *Oncology Nursing Forum*, Vol. 31, No 4, 2004 and *Journal of Supportive Oncology 2003*, 1: 206–215.

Memorandum by Alison Davis, National Co-ordinator, No Less Human (a Group within SPUC)

SUMMARY OF SUBMISSION TO THE SELECT COMMITTEE ON THE ASSISTED DYING FOR THE TERMINALLY ILL BILL

FROM

ALISON DAVIS, NATIONAL CO-ORDINATOR, NO LESS HUMAN (A GROUP WITHIN THE SOCIETY FOR THE PROTECTION OF UNBORN CHILDREN)

No Less Human (NLH) exists to protect and promote the equal right to life of all disabled people throughout their lives. NLH opposes the legalisation of euthanasia.

NLH argues that it is not in the best interests of people who are suicidal to have their wish to be killed (or assisted to die) granted. To do so, a doctor would have to agree that the patient was "better off dead," thus the real autonomy would lie with the doctor, not the patient.

The supposed "safeguards" to the Bill ensure only that certain sorts of people, those regarded as inherently "right to want to die" and "better off dead," would have their request for euthanasia acted upon. They would be given help to die while others, who might well be equally desperate to die, would be helped to live. NLH argues all suicidal people should be given help to live until they die naturally. A truly good death can be achieved naturally with appropriate palliative care given either in a Hospice setting or by "hospice at home" and this is real "death with dignity."

Every human being has an intrinsic, infinite value and an innate and inalienable right to life. Euthanasia would deny this most basic of human rights.

The Bill mentions "unbearable suffering" as a qualifying condition for euthanasia, but this is an entirely subjective judgment, and is not determinable by a doctor. Euthanasia for this reason would thus be entirely without "safeguards," because no one could refute a person's claim to be "suffering unbearably." The provision in the Bill for suffering people to receive pain relief medication is entirely spurious, as it is in fact already available.

Disabled and ill people are afraid of euthanasia being legal. NLH notes that the supposed "right to die" is often a code term for the "duty to die" because society refuses to provide the support disabled and sick people need. We note that over 10,000 Dutch people carry "anti euthanasia passports" because they are afraid of being killed without their consent. Euthanasia is cheaper than caring for disabled and sick people.

It is misleading to suppose legalised euthanasia and increased funding for palliative care could coexist. NLH suggests that instead of funding euthanasia, increased funding should be available for palliative care and other support services for sick and disabled people.

The author of this submission is severely disabled. She once wanted to die and attempted suicide several times. Under the terms of this Bill she would have qualified for "assisted dying." Euthanasia would have robbed her of 19 years of life, and nobody would ever have known that the future held something better for her. The Bill requires a waiting period of 14 days during which a qualifying person may change their mind. The author of this submission wanted to die for 10 *years*.

1. Introduction

This evidence is submitted on behalf of No Less Human, a group within the Society for the Protection of Unborn Children for disabled people, their families and carers. No Less Human (NLH) campaigns to secure in law the equal right to life of every disabled person, from conception to natural death.

This submission seeks to demonstrate that the Assisted Dying for the Terminally Ill Bill would compromise the right to life of disabled and sick people, and further undermine their dignity and status. NLH holds to the truth that it is fundamentally wrong to kill vulnerable people, whether or not they have requested death.

NLH strongly believes that illness and disability should not be used to justify deliberate killing, and that those who are terminally ill or incurably disabled should be treated using the same ethical code as would be applied to any other person.

2. The Question of Autonomy

2.1 The case for euthanasia is often argued on the basis of the concept of autonomy, that is, the individual's freedom to make decisions about his or her own treatment. However, to use autonomy as an argument for allowing "voluntary" euthanasia involves a misunderstanding of the concept, overlooking the principle that the freedom to make decisions entails a responsibility to act ethically. Personal autonomy should be regarded as a "right" only when it is exercised responsibly in the best interests of the individual concerned.

2.2 "Best interests" are generally understood, as is reflected in case law,[10] to include basic factors such as preserving life, maintaining or restoring health and minimising suffering. In recent years the interpretation of "best interests" has begun to be extended to include the "wishes and feelings" of the individual concerned,[11] but this is problematic for many reasons.

2.3 Not least of these reasons is the case of suicidally depressed people. They "wish" to die and "feel" that death is in their best interests, but any doctor worthy of his or her profession would nevertheless overrule these wishes and feelings and institute treatment to save and/or sustain the life of such a person. In the same way even if a patient strongly "feels" that a particular drug would benefit him and "wishes" it to be prescribed, a doctor should prescribe it only if s/he feels it will actually benefit his patient's medical condition. Relying on "wishes and feelings" suggests that life is not a basic good unless the individual recognises it as such. Similarly, relying on a subjective estimation of a person's "quality of life" is not compatible with ethical medicine.

If a person is depressed, this may well be warping his or her judgment, sometimes to the extent of feeling suicidal. Any person who is, or may be, depressed deserves a specific response and appropriate treatment, by drugs, counselling or changing the person's environment to some extent. This should be the case whether or not s/he is the sort of person generally regarded as "better off dead."

2.4 Doctors have a duty to act in the true best interests of their patients. This can never include deliberately killing them. This does not mean that No Less Human advocates the use of futile or disproportionately burdensome treatment, given in a vain attempt to prolong the process of dying, or that the process of dying should be artificially prolonged. Once it has been established that continued aggressive surgical or medical treatment is futile or excessively burdensome it may be stopped, and palliative care intensified.

2.5 However, this must never be taken to mean that doctors, in the name of "beneficence" institute treatment regimens the purpose of which is to hasten death. Neither must it mean that doctors may cause the deaths of those who are not actually dying. Decisions about which treatments are futile or disproportionately burdensome, and who is irremediably dying are the proper realm of medical ethics. Decisions about whose "quality of life" is such that they are "better off dead" have no place in ethical medicine. Decisions to cause or hasten death masquerading as "beneficence" are unequivocally unethical, and are incompatible with the human rights and dignity of all vulnerable people.

2.6 If a doctor were to "assist" a patient to die under the terms of this Bill s/he would have to agree that the patient was "better off dead" since surely no doctor would kill a person for whom it was believed there was still "hope." Thus the real autonomy would lie with the doctor, not the patient. Euthanasia would be seen as a duty where the doctor agreed that the patient was "better off dead", and the doctor would be seen as negligent if s/he failed to perform euthanasia in these circumstances. Indeed, the Bill requires that a doctor who has a conscientious objection to euthanasia must refer a patient who requests death to a doctor who has no such objection (sections 7.2 & 7.3), thus compelling doctors to be involved, albeit obliquely, in the process of euthanasia.

In this latter respect it might perhaps be argued that if a doctor does not wish (perhaps on conscience grounds) to continue to treat a patient who requests this, the Bill, in the interests of consistency, should require that doctor to find another medical practitioner who is prepared to do this. If it is mandatory to find someone who will follow the patient's wishes in one situation, why should it not be mandatory in the reverse situation? Failing to do so indicates clearly that the whole focus of this Bill is to ensure the killing of certain sorts of people—those who are generally regarded as "right to want to die."

2.7 Legalising "voluntary euthanasia", even with the supposed "safeguards" included in the Bill, would suggest that some sorts of "volunteers" (those who satisfy the qualifying conditions) are "right to want to die" (ie have lives which are objectively not worth living) leading to a view that life for such people is a disbenefit whether or not they have actually requested euthanasia.

[10] *Re F* (Mental Patient: Sterilisation) [1990] 2 AC1, 78.

[11] *Withholding and withdrawing life-prolonging treatments: good practice in decision making:* Draft guidance from the Standards Committee of the General Medical Council May 2001; *Withholding or Withdrawing Life-prolonging Medical Treatment: Guidance for decision making.* British Medical Association. BMJ books 1999; *Mental Ccapacity Bill.* Presented to Parliament by the Secretary of State for Constitutional Affairs—June 2004.

2.8 It is sometimes suggested that since attempted suicide is no longer punishable, assisted suicide should be allowed. However, the British Suicide Act 1961, whilst decriminalising attempted suicide, created no legal right to commit suicide, and made assisting suicide a serious criminal offence punishable by up to 14 years imprisonment.[12] The debates on this Act show that the law was changed to show compassion to people who were so desperate they wanted to die, not to acknowledge that attempting suicide was either right or appropriate.

2.9 Relaxing the absolute prohibition on killing by euthanasia would undermine, not promote autonomy. In an attempt to exercise autonomy by requesting euthanasia, the person's own autonomy would be forever destroyed.

3. The Right to Life

3.1 Every human being has intrinsic, infinite value, and has an innate and inalienable right to life. The Human Rights Act 1998 states "Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law."[13] Without the right to life, all other rights become meaningless, including the right to personal autonomy.

3.2 The Law Lords, in their ruling in the case of Dianne Pretty, ruled that this article means what it says. Lord Bingham of Cornhill commented that "The article protects the right to life and prevents the deliberate taking of life save in very narrowly defined circumstances. An article with that effect cannot be interpreted as conferring a right to die or to enlist the aid of another in bringing about one's own death."[14]

3.3 Pro euthanasia advocates often try to argue that if there is a "right to life" there must also be a corresponding "right to die." This is not the case. The right to life is an inalienable right, a right of which an innocent person may not be deprived and which one cannot, in justice, deprive oneself of by intentionally bringing about one's own death. This is true whether the killing is by commission or omission, and whether or not it is brought about for supposedly "merciful" reasons.

3.4 "Voluntary" euthanasia would intentionally deprive an innocent person of his or her life, and is thus always wrong. Allowing it would send out a strong message that some human beings have less worth and less dignity than others, and that some human lives have no value at all—the opposite of the reality that every human being has innate and infinite value.

4. The "Qualifying Conditions" Ensure that the Most Vulnerable are Not Safe

4.1 The Bill prescribes as "qualifying conditions" that the person requesting death must be mentally competent, have a terminal illness, be "suffering unbearably" and have been informed of the alternatives to euthanasia. Far from "safeguarding" anything, these requirements in effect prescribe who is to be considered "right to want to die" and thus helped to bring about their own death.

Those who may be equally suicidal but do not have obvious disabling conditions are considered "wrong to want to die" and are helped to live.

4.2 Such value judgments about the lives of vulnerable people are incompatible with their equal, innate and inalienable right to life.

4.3 It has been found that where euthanasia is legalised "with strict safeguards" such criteria are liable to be stretched or overlooked. Once it is decided that certain people are "better off dead" the fact that they might not have actually volunteered for euthanasia is not necessarily a safeguard against euthanasia being imposed upon them. For instance in Holland at least 900 people had their lives ended "without an explicit request" in 1995, the last year for which full figures are available, amounting to one in five of all reported euthanasia cases.[15] In 22 per cent of Dutch euthanasia cases there had been no "explicit request" by the person concerned, and 50 per cent of those subjected to this killing without consent were competent at the time of their death.[16]

[12] Debate on the Suicide Act. Hansard. 19 July 1961. Cols 1425–1426.

[13] Human Rights Act 1998. Schedule 1, Part 1, Article 2 "Right to life." 1. London. The Stationery Office.

[14] House of Lords. Opinions of the Lords of Appeal for Judgment in the Cause: The Queen on the Application of Mrs. Dianne Pretty (Appellent) v. Director of Public Prosecutions (Respondent) and Secretary of State for the Home Department (Interested Party) on 29 November 2001 [2001] UKHL 61.

[15] H Jochemsen & J Keown. Voluntary euthanasia under control? Further empirical evidence from The Netherlands *Journal of Medical Ethics* 1999; 25: 16–21.

[16] Jochemsen & Keown Voluntary euthanasia under control? Ibid at p 18.

The single study yet published from Belgium, where euthanasia was legalised in May 2002 showed that 30 per cent of euthanasia cases there were non-voluntary.[17]

The latest annual report released by the Oregon Department of Human Services notes that in 2003 two people took lethal prescriptions they had received in 2002 and one took a lethal prescription received in 2001.[18] This strongly indicates either that the rule that the patient must have only six months or less to live is being ignored, or that doctors are incapable of accurately making such diagnoses.

4.4 In Holland it has been found the mentally disabled people are particularly vulnerable to euthanasia decisions. A study found that 44 per cent of the deaths of such people living in institutions involved an "end of life decision" though only two of the 97 people concerned had "expressed a wish to die"—a "choice" which was inferred if the person pulled out a feeding tube.[19]

4.5 Elderly Dutch people have also been vulnerable to the same sort of decision-making.[20] An 84 year old lady with heart problems and osteoporosis who said she did not want to die was killed by her doctor who said she was "wretched . . . her bed soaked in urine, her room stinking from bed ulcers and necrosis in her heel." The court that tried this case said he had made an "error of judgment" but had "acted honourably and according to his conscience"[21] What this lady needed was good nursing care, but she was killed because her doctor had a negative attitude towards suffering people.

4.6 Pro euthanasia advocates often suggest that depression would be a contra-indication for allowing euthanasia. However, this is not a requirement of the Bill, which mentions only that a psychiatrist's view must be sought if a doctor believes the patient is not competent to choose to die. Baroness Finlay of Llandaff has noted that 20 per cent of medically ill patients have a treatable depression, but not all have their condition recognised or treated. Indeed one in four of the population has had a mental disorder at some time, and many of such people have experienced depression.[22]

In fact it is notoriously difficult to assess treatable depression in those with advanced illnesses.[23] The will to live often fluctuates widely over the course of an illness or progressive disability, and often disappears when proper care and attention is paid to the person's fears, symptoms and emotional needs.[24] Most depression can be treated in the right environment. Euthanasia merely suggests to the suffering person that s/he is right to feel there is no hope.

4.7 The "qualifying conditions" stated in the Bill cannot prevent "abuse" of the law, because a law allowing euthanasia is in itself an abuse of the inherent, inalienable right to life of vulnerable people.

4.8 NLH notes that the Bill's title is misleading. The term "Assisted Dying" does not make it clear that the aim of the Bill is to allow vulnerable people to be killed. It is also misleading in that the Bill actually allows for active killing (eg by legal injection) (section 1 (2)) as well as facilitating a patient to take his own life.

5. The Question of "Dignity"

5.1 The phrase "death with dignity" is very often used by euthanasia advocates to mean the deliberately procured death of a vulnerable person. It implies that such people are only "dignified" in death. No Less Human strongly disagrees that this is the case.

5.2 In high profile cases in the media in Britain and in other countries of vulnerable people who wanted to die by euthanasia, it is consistently reported that they are requesting the right to "die with dignity" as if a natural death could not possibly be dignified.[25] This highlights the terrible, and false, dilemma that is presented to vulnerable people. It is strongly suggested by the pro-euthanasia lobby that the choice is between euthanasia and an appallingly "undignified" painful death. This has particularly been the case in high profile cases

[17] L Deliens, F Mortier, J Bilsen, M Cosyns, S R Vander, J Vanoverloop *et al.* End of life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356: 1806–11.

[18] "Assisted suicide numbers up in Oregon." By AM News Staff. *American Medical Association News* 5 April 2004.

[19] G M Van Thiel *et al.* Retrospective study of doctors' "end of life decisions" in caring for mentally handicapped people in institutions in the Netherlands *BMJ* 12 July 1997; 315: 88–91.

[20] T Sheldon. Euthanasia endorsed in Dutch patient with dementia. *BMJ* 1999; 315: 327.

[21] T Sheldon. Dutch GP found guilty of murder faces no penalty. *BMJ* 3 March 2001.

[22] Debate on Mental Incapacity. House of Lords. Hansard. 18 December 2002. Column 765.

[23] D W Kissane & B J Kelly. Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill. *Australian & New Zealand Journal of Psychiatry*. 34(2): 325-33.

[24] Yvonne Y W Mak et al Patients' voices are needed in debates on euthanasia. *BMJ* 2003; 327: 213-215.

[25] "I helped my father die" by Jacqui Paterson. *Real* 25 March–4 April 2003. The daughter of Reginald Crew, who had Motor Neurone Disease and was taken to the Dignitas Clinic in Switzerland for "assisted suicide" said after his death "He may have been stripped of dignity if life, but he got it back with his death.".

involving people with Motor Neurone Disease.[26] The truth is that with proper palliative care, including all necessary hospice support, the choice is between deliberate killing and a peaceful, truly dignified death made as pain free as possible by experts in pain control.[27] [28]

An Editorial in the British Medical Journal has noted that "appeals to dignity are either vague restatements of other, more precise, notions or mere slogans that add nothing to an understanding of the topic. . . Phrases like "death with dignity" . . . have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred."[29]

5.3 Lord Justice Tuckey, in the House of Lords judgment on the case of Dianne Pretty, who sought permission for her husband to "help her die," said "In our view the right to human dignity which is enshrined in Article Three (of the Human Rights Act 1998) is not the right to die with dignity, but the right to live with as much dignity as can possibly be afforded until that life reaches its natural end."[30] No Less Human shares this view, and promotes the truth that vulnerable people have a right not to assisted death, but to support to enable them to *live* with dignity until they die naturally.

6. The Question of Pain

6.1 Fear of pain and suffering is a reason why many people feel euthanasia should be legal. However, in Holland, even some doctors who practice euthanasia admit that pain is not the usual reason for euthanasia requests.[31] In one study it was found that in Holland only in 5 per cent of cases was pain mentioned as the most important reason for requesting euthanasia.[32]

A Canadian study noted that while public support for euthanasia is highest for physical pain and lowest for "loss of purpose and meaning" "in reality patients in the latter circumstances may be more characteristic of those who would actually make requests for hastened deaths."[33] In Oregon, where euthanasia is legal, the most commonly cited reasons for requesting it are "loss of autonomy, a decreasing ability to participate in enjoyable activities and loss of control over bodily functions."[34]

6.2 The Bill states as a "qualifying condition" that the person requesting "assisted dying" must be experiencing "unbearable suffering" and the definition of this acknowledges that it is an entirely subjective judgement. Allowing euthanasia for "unbearable" suffering relies on such a condition being determinable by the doctor. In fact pain is entirely subjective, and hospice doctors note that "a clinician is only partially qualified to determine" it.[35] Euthanasia for reasons of pain would thus be entirely without "safeguards" (see above section 4) because no one could refute a person's claim to be suffering "unbearably."

6.3 Many pro euthanasia campaigners definite "unbearable suffering," as a qualifying condition for euthanasia, to include such symptoms as incontinence, vomiting, bedsores, breathlessness, oedema and insomnia.[36] The reality is that such symptoms can almost always be relieved with the help of good nursing and/or palliative care either given in a hospice setting or at home. It is not sufficient for a doctor simply to "inform" a patient about the alternatives to euthanasia. Unless the patient is given first proper information about such alternatives, including nursing, palliative and hospice care and then easy access to these alternative treatments the impression will persist that euthanasia is the only sensible option for those with intractable pain.[37]

6.4 The provision in the Bill "for a person suffering from such a condition to receive pain relief medication" is entirely spurious. Such medication is already available and it does not need a Bill to underline its availability. Including this clause merely serves to suggest that euthanasia and good care are equally acceptable alternatives.

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[26] "Farewell to wife who campaigned for right to die" by a Correspondent. *The Times* 24 May 2002. This article, reporting on the death of Dianne Pretty reported that choking and asphyxia are "often" caused by Motor Neurone Disease.

[27] "The will is not to die but to flee" by Melanie Phillips. *The Observer*. 19 March 1995.

[28] T O'Brien, M Kelly and C Saunders. Motor neurone disease: a hospice perspective. *The Lancet* 1992; 304: 471-473.

[29] "Dignity is a useless concept" *BMJ* 2003; 327:1419-20 (20 December 2003).

[30] In the High Court of Justice Queen's Bench Division Administrative Court between The Queen (on the application of Mrs Dianne Pretty) Director of Public Prosecutions (Defendant) Secretary of State for the Home Department (Interested Party), (1) Medical Ethics Alliance (2) Society for the Protection of Unborn Children (3) Alert (Intervenors) 18 October 2001.

[31] "Trust me, I'm a doctor . . ." *Electronic Telegraph* 15 April 2001.

[32] Robert Gerrit van der Wal, & J M Dillmann. Euthanasia in the Netherlands. *BMJ*. 21 May 1994.

[33] 24 K G Wilson et al. Attitudes of Terminally Ill Patients Towards Euthanasia and Physician Assisted Suicide. *Archives of Internal Medicine* 2000; 160: 2454-2460.

[34] "Assisted suicide numbers up in Oregon" by AM News Staff. *American Medical Association News* 5 April 2004.

[35] Joint Palliative Care Briefing paper June 2003. Ibid at p 23.

[36] "Why, after 45 years, I can no longer support the Liberal Democrats" by Ludovic Kennedy. *The Times* 19 May 2001.

[37] "The Patient (Assisted Dying) Bill." A joint briefing paper by the Association for Palliative Medicine and the National Council for Hospice & Specialist Palliative Care Services. June 2003.

6.5 It is commonly thought that the use of opiates (morphine and diamorphine) and sedatives in the terminal phase of an illness shorten life. The pro euthanasia lobby uses this "fact" to argue that "euthanasia" is already going on, and should therefore be put on a legal footing. However, there is irrefutable evidence that this is not the case.[38]

The Association for Palliative Medicine and the National Council for Hospice & Specialist Palliative Care Services have suggested that it is "misleading and mischievous" to suggest that the law needs to change for comprehensive and effective management of distress at the end of life to be made available.[39]

6.6 One senior Hospice doctor has estimated that at least 95 per cent of physical pain can be completely and easily relieved, and "100 per cent of patients can be helped."[40] When pain-relief drugs are not working pain can often be relieved by non-drug methods such as TENS ("Transcutaneous Nerve Stimulation") machines, acupuncture or physiotherapy. When euthanasia was legalised in Holland there was virtually no funding for palliative care, and its quality there even now is questionable.[41]

A study in the Journal of Palliative Medicine has shown that despite the claim that pain management for dying people would improve after the legalization of euthanasia in the US State of Oregon, in fact it got worse. Half of family members of dying people between 2000 and 2002 said the dying person's pain was "moderate" or "severe" before they died. Before 1997 (when euthanasia was legalized) only 1/3 said this. Dying people between 2000 and 2002 were twice as likely to have "moderate" or "severe" pain in their last week of life as those before 1997, an indicator that hospice care has deteriorated since euthanasia was legalized in Oregon.[42]

6.7 Hospice doctors have observed that "The prospect of good quality end of life care and fulfilled needs helped alter (patients') perceived reality and led to re-evaluation of their desire for death . . . . the desire for euthanasia must not be taken at face value."[43] Legalised euthanasia militates against the development of good palliative care and hospice services. If killing is seen as acceptable, less attention is paid to providing support services for those who suffer.

7. Fears of Disabled and Ill People

7.1 No Less Human has spoken out on all the recent cases brought by the pro euthanasia lobby. These matters are of direct relevance to the members of NLH, all of whom are disabled or ill people or families or carers of such people. Our membership includes people who are terminally ill, their families, and families of vulnerable people who have died. We note that the supposed "right to die" is a kind of codeword for what is often a "duty to die" because society refuses to provide appropriate support for our needs.

7.2 The lack of options for many disabled people was made clear by the case of Larry McAfee, an American quadriplegic, who used a ventilator, and had been living in a succession of nursing homes and hospitals.[44]

He requested that his ventilator be turned off, and the judge hearing the case commented "Mr McAfee is not committing suicide . . . his ventilator would not prolong his life but instead would prolong his death." In other words he was expressing the opinion that life for a disabled person is tantamount to death. Before Mr McAfee could take his own life, he was offered a place in an independent living project for disabled people. He took that option and began working towards getting a job. Euthanasia would have robbed Larry McAfee of life before it could be shown that it was not his disability but his living conditions that were making him want to die.

7.3 Negative attitudes towards disabled and sick people, with the assumption that such people would be "better off dead" have been reported in the UK. Sue Maynard-Campbell, who uses a wheelchair and is Vice-Chair of an NHS Trust, went into hospital for a chest infection in 1998 and found that "Do Not Resuscitate" was written on her medical notes.[45] The doctor had decided she had a "poor quality of life" after, she says, speaking "no more than six words" with her. The doctor was unrepentant, and now she refuses to go into hospital. Jane Campbell, a member of the Disability Rights Commission was told when in hospital that she would not be put on life support because "you don't want to live like that" and that she would not be ventilated because she would not live "a full and active life" afterwards. She was afraid to go to sleep for the rest of her

[38] Sykes & Thornes. Sedative use in the last week of life and the implications for end of life decision making. *Archives of Internal Medicine* 2003: 163: 341–44 & Systematic review. *Lancet Oncology*. April 2003.

[39] Joint Palliative Care Briefing Paper June 2003. Ibid.

[40] Commentary by Dr Robert Twycross, Macmillan Clinical Reader, Oxford University. July 1997.

[41] R Cohen-Almagor. Dutch perspectives on palliative care in the Netherlands. *Issues in Law & Medicine*. 2002; 18: 111–26.

[42] "Pain Management Plagues Dying Patients" Associated Press. *ABC News* 30 July 2004.

[43] Y W Mak, G Elwyn & Ilora Finlay G. Patient's voices are needed in debates on euthanasia. *BMJ* 2003; 327: 213–5.

[44] "The Right to Die" *The Times* 8 September 1989.

[45] "How dare anyone tell me I am not worth saving" *Sunday Mirror* 30 April 2000 + Personal contact.

hospital stay, and describes this approach as "ignorant, ill-informed, heartless and calculating."[46] If euthanasia were legal, such negative judgments about the value of disabled lives would only become more prevalent, and would appear to be entirely justified.

7.4 NLH notes that the Patient (Assisted Dying) Bill, the current Bill's predecessor allowed "a competent adult suffering unbearably from a terminal *or serious incurable physical illness*" to request "medical assistance to die." We suggest that this is evidence of the real intention of the pro euthanasia lobby, and of parliamentarians who support them, and that it is only a matter of time before the qualifying criteria for euthanasia would be widened to include people with non terminal conditions. Once it is accepted that killing is an acceptable solution to the problems of vulnerable people, it is inevitable that the number of people allowed to opt for it will increase.

7.5 Members of No Less Human fear that the authority to "assist" the deaths of sick and disabled people would become a duty to kill. Many vulnerable people feel afraid that they might be killed without their consent, because this is something that happens regularly where euthanasia is legal. We note that over 10,000 Dutch people now carry "anti euthanasia passports" because they are afraid of being killed by euthanasia.[47] We recognise the dangers of such a system, not least the fear of what would happen if such a document were mislaid, or simply not made available to the doctor, but cite it simply as an indication of the level of fear among people who live in a country where euthanasia is legal, even though it is allegedly "strictly controlled."

7.6 Many sick and disabled people fear being a burden to their families and caregivers. If euthanasia were legal it would send out a strong message that vulnerable people are right to feel burdensome, and that euthanasia is "the answer" to this sort of worry.

8. Economics

8.1 There is a likelihood that already sparse resources for disabled and sick people would be further reduced if euthanasia were legalised, because of a subliminal view that money is better spent on those who will recover.

8.2 It was reported in the full Government report from Holland in 1991 that ". . . it was gratifying to note that only one patient had non-voluntary euthanasia because there was the need for a bed."[48] To call it "gratifying" that such a killing happened "only" once shows how routine killing becomes once it is legalised.

NLH notes that in June 2004 a hospital ward sister was jailed for "attempting to kill" two elderly "bed blocking" patients in a drive to free up NHS beds.[49] She would tell doctors that patients who were actually comfortable were in pain, prompting doctors to prescribe diamorphine which they did not need, then lie them flat so that their breathing became laboured. If euthanasia were legal, we question whether such actions would still be punished, particularly if the patients concerned were terminally ill and unable to express an opinion about wanting to die.

8.3 It is misleading to suppose that legalised euthanasia and increased funding for palliative care could go hand in hand, as the Bill proposes. The former would militate against the latter. There would be costs in implementing any system of legalised euthanasia, for instance in setting up the proposed "Monitoring Commission." (section 14.) No Less Human suggests that instead of funding deliberate killing by euthanasia, increased funding should be provided for palliative care, and other support services for sick and disabled people, to enable them, as the Hospice movement puts it, to "live until they die."

9. A Personal Experience

9.1 The concerns raised above have a particular personal resonance for the author of this submission. I have spina bifida, hydrocephalus, emphysema and osteoporosis, and use a wheelchair full time. I experience severe spinal pain on a daily basis, and even morphine cannot always control my pain. When the pain is at its worst I cannot move, speak or think, and it can go on for hours. There is no prospect of relief; in fact it is very likely that the pain will get worse.

9.2 Nineteen years ago, when my doctors believed that I was terminally ill, I decided that I wanted to die, due to a combination of factors including my severe physical pain. It was a settled wish that lasted about 10 years, and during the first five of those years I made serious suicide attempts several times. I strenuously attempted to ensure that I succeeded, and was saved only because my friends found me in time, refused to accept my view that my life had no value, and ensured I was given emergency treatment in hospital, which was given against my will.

[46] "Your life in their hands" by Lord Alton of Liverpool. *The War Cry* 24 May 2003.

[47] "Dutch carry cards that say: Don't kill me, doctor" by Rachel Bridge. *Sunday Telegraph* 18 October 1998.

[48] The Remmelink Report, 1991. Narrative accompanying the data on Nonvoluntary and involuntary euthanasia (tables 6.4–6.8).

[49] "Nurse jailed for trying to kill 'bed blockers'" by Russell Jenkins. *The Times* 19 June 2004.

9.3 If the "Form of Declaration" proposed by the Bill been available then I would have signed it. Had the Bill been law, I would not now be writing this submission. I would have died, and no one would ever have known that the future held something better for me. Even though I have the same degree of pain as I had 19 years ago, I have come to value my life, but it took 10 years for that to happen. Euthanasia does not allow for any mistakes. It is not reversible. Euthanasia under the terms proposed in this Bill would have robbed me of the last nine years of my life, during which I have worked to promote and protect the right to life of disabled people in this country, and founded a charity to provide a better life for disabled children from poor communities in India.

9.4 I anticipate that the Committee may conclude that euthanasia under the Bill would have been denied to me because I was "depressed." Apart from the arrogance of presuming to know my state of mind when they did not even know that I existed, the truth is that the Bill does not mention depression as a disqualifying factor (see section 4.6) In fact, most requests for killing do stem from some form of depression, and the availability of euthanasia would simply mean that less attention would be paid to trying to treat it.

9.5 If this Bill had been law when I wanted to die, the doctors who treated me specifically against my wishes would not have been able to do so. If they had a conscientious objection to legalised killing, they would have been obliged to refer me to a doctor who would carry out my wishes and end my life. The Bill requires that there be a "waiting period" of 14 days during which a qualifying person may change their mind about wanting to die. I wanted to die for 10 years.

9.6 When my friends prevented me from taking my own life I was extremely angry with them; now I am eternally grateful. Then I sincerely wished to die and felt my life had no value but, as is the case with many desperate people, those wishes and feelings did not correspond with what was truly in my best interests. This Bill would rob people of the sort of treatment I was given, even though I did not want it at the time. I urge the members of the Select Committee to bear in mind my case during their deliberations.

10. Conclusion

10.1 Euthanasia is often presented as being a "merciful" or "compassionate" way to treat suffering people. However, compassion does not mean simply giving people what they want, or say they want, or what others think they "ought" to want. Similarly "mercy" does not mean killing in the name of "preventing suffering."

True compassion and mercy entail wanting the best for suffering people and having empathy with their suffering, staying with them as they suffer, offering whatever treatment may help and attempting to help them recover a sense of hope and of being loved. I was fortunate in that my friends understood the real meaning of both compassion and mercy, and demonstrated both in their care and concern for me.

10.2 Euthanasia simply colludes in the fallacy that there is such a thing as a "life not worthy to be lived." It suggests that suffering people are "right to want to die" and represents the ultimate rejection of vulnerable people. Deliberate killing is the opposite of "mercy" and "compassion" and should never be legalised. Vulnerable people like the members of No Less Human deserve better than being told that death is in the best interests of those who suffer. What we need is help to live with dignity, until we die naturally.

10.3 No Less Human urges this Select Committee not to legalise "assisted dying", which would give credence to the claim that there is such a thing as a "life not worth living" or "not worthy to be lived."

August 2004

Memorandum by R George, MA, MD, FRCP, Senior Lecturer Centre for Bioethics and Philosophy of Medicine; Consultant Palliative Medicine to: Ealing PCT; Hospice in the Weald and Department Oncology UCL Hospitals Trust (1987–2003, now honorary)

I do not consider or foresee a place for Assisted Dying or therapeutic killing (AD/TK) in any clinical practice. A deep personal intuition, independent of my beliefs, makes me very suspicious of the way in which the case is being presented and rebutted. It seems to me that the common ground of debate must be the rights and freedoms of individuals, where if anything the vulnerable take priority.

I declare my ethical premisses and clinical facts as foundations from which to explore AD/TK from first principles and clarify my concerns about the presentation and substance of the case in either direction. To make the analysis real I use the empirical literature to refute or support my analytical conclusions and the most difficult cases from my own career[50] to test the current and proposed legislations' impact on my practice. I am triangulating to try to avoid these pitfalls: theoretically of abstruse mind experiments[51], empirically of

[50] Approaching 20,000 cases.

[51] There are many examples of *reductio ad absurdum* amongst which is the policeman's dilemma.

generalisation and excessive utility[52], and clinically of emotivism[53]. This is mandatory, as the impact of legalising AD/TK are so profound on society's view of its members and its proposed demands on the professions to reverse the various codes and duties of all clinical specialities relating to life and death.

I. Foundations

A. *Clinical facts*

1. Death is inevitable and in that dying, the burden of disease or causal gradient as death approaches is so great that the matter for the patient is not bringing death on, but either clinging to life or letting go of it. Palliative care clinicians know this, society and other clinicians tend not to;

2. Suffering is extremely complex, part of our humanity and only a small element is physical. To resolve or mitigate suffering requires skilled engagement and perseverance based in specific training and multidisciplinary practice;

3. Non-specialist clinicians[54], ethicists and society misunderstand the use and effects of opiates and sedatives at the end of life. Presuppositions that they hasten death are simply wrong.

B. *Ethical premisses*

1. To preserve individual freedom and that of the vulnerable in particular;

2. The value of life must matter to society and not just the individual to make any sense of freedom;

3. Society and Parliament continue to have a presumption in favour of life;[55]

4. Belief is just that: neither position in this debate holds the moral high ground, eg secular and religious fundamentalism are equally repugnant;

5. I distinguish clearly between killing and letting die;[56]

6. Justification & motive are not necessarily the same thing.

Argument 1: AD/TK as a right: The protagonists appeal to autonomy. Since autonomy is a liberty, an entitlement can override it only if justice (public interest) overwhelms it or if others' matched liberties are indisputably preserved.[57]

1. The right to life and freedom to die (suicide) meet this criterion, but the right to die can only do so if no one is killed without their request.

2. The decision for Physician AD/TK remains with the doctor and the promotion of *individual* patient autonomy requesting it is still "virtual". Therefore, patients have little more control over their death than before.

3. Once therapeutic killing is introduced, it behoves clinicians to discuss euthanasia as part of management and informed consent with all patients facing death. This is arguably as undermining to liberty (as it may infer a duty) as it is promoting of it[58], especially as it will be an unwelcome conversation in all but a few. Finally,

4. TK, without explicit request, or of the incapable, is the ultimate violation of freedom. It seems to have a lot in common with the collateral damage that is so repugnant in current armed conflicts. The protagonists' defence is that with proper safeguards, very few would die in this way.

Can society really accept relegating any individuals to status of unintended casualties? I suspect not: all opinion surveys in favour of AD/TK assume and expect safeguards for the vulnerable. None from my systematic review of the literature seeks views if no safeguards are possible.

[52] Illegitimate inferences from limited studies or other cultures about practice in general, and the UK in particular.

[53] Many clinicians carry the burden of witness in cases where their skills have run out and people have suffered, or they feel that they have killed with "the last injection", when they have done nothing of the sort.

[54] GPs care on average for less than five dying patients a year and educational programmes consistently find that their ability and confidence in using drugs at the end of life is limited. In a recent small, informal study (George, unpublished) less than 10 per cent of teaching hospital consultants were able to give correct analgesic regimes in a series of simple case studies.

[55] This is born out clearly in the Mental incapacity Bill, *re R* and most recently in *re Burke*.

[56] Notwithstanding that in many situations there is no distinction between acts and omissions.

[57] The current debates are over identity cards and smoking in public places.

[58] The Oregon Data (Oregon Death with Dignity Act. http://www.dhs.state.or.us/publichealth/chs/pas/pas.cfm. 2004.) show a rise in "being a burden" as a reason to request AD from 1:5 to 1:3 over the period since the Bill came in.

I now come to the antagonists. Published data show legislation to have failed in all countries where it is measured to limit or control non and involuntary euthanasia and opponents see a slippery slope in view[59]. This is the area of particular concern to the disabled as another potential violation of their Human Rights[60]. They cite members' experiences of coercion to refuse resuscitation or intensive care support for acute disease when admitted to hospitals.

Argument 2: The Slippery Slope. Philosophically, this argument needs both a causal initiator and a "gradient". Antagonists cite medical blood-lust or moral turpitude, which whilst possible in a tiny minority, is generally risible[61]; procedural deterioration from idleness, which is insufficiently strong; and economics, which as the Dutch are finding, whilst a consequence is probably not a cause[62]. However, we are left with the fact that legislation in Holland, at the most conservative estimation[63], after an initial rise has not changed significantly over 10 years such that one comes out with a ratio of about 1:5 euthanasias being without consent.[64]

Argument 3: My explanation of the Data—A paradigm shift of death from harm to medical good. A much more coherent hypothesis is that legalisation of AD/TK effects a paradigm shift in thinking, much as any new treatment, with a phase-lag in implementation as doctors and society normalise and integrate therapeutic killing into perception and legitimised practice. Quite rightly, assistance to die then becomes a treatment option in all patients[65].

1. This view of AD/TK introduces to medicine the new paradigm of "therapeutic killing" for perceived suffering in anyone.

2. Our imperatives then shift to diagnosis and discussion with all who are competent—a problem highlighted by the literature[66]—and,

3. By extension, an obligation in some incompetent people, regardless of pathology or prognosis, to consider death a best interest and therapeutic killing a necessary expression of our duty to care. This argument accounts for the extension of TK to the incapable, minors and mentally ill through case law that we see in the Dutch legislation's failure to limit or control TK to voluntary, capable request[67].

4. It also preserves the integrity of its doctors, for the rise and equilibration in numbers of patients killed "therapeutically" and the extension to all patients regardless of diagnosis or capacity now becomes a laudable and expected finding[68].

5. Finally, once a "medical good", therapeutic killing crosses the equation of any calculus of utility and becomes a legitimate consideration in resource management[69].

[59] The much-quoted Oregon experiment cannot answer these questions. Their monitoring does not include death certificate studies or direct questionnaires of doctors' practices outside the law or in their practice that has not gone through the Dying With Dignity Act Protocol. Nothing has come up on systematic review.

[60] Brook U. The attitude of young adults with chronic disease or handicaps towards enforced treatment and euthanasia. Patient Education & Counseling 1999; 38(1):43-8.; Batavia Al. Disability and physician-assisted suicide. The New England Journal of Medicine 1997; 336(23):1671. Coleman D, Drake S. A disability perspective from the United States on the case of Ms B. Journal of Medical Ethics 2002; 28(4):240.

[61] There is one nursing study of supposed euthanastic acts in ITUs in which a handful of nurses claim to have shortened well over 20 times and in one case over 100 off their own bat (Asch DA. The Role of Critical Care Nurses in Euthanasia and Assisted Suicide. New Eng J Med 1996; 334:1374-1379.). The only relevance of Shipman to our debate is that it has meant that many patients are now denied proper analgesia and sedation when they need it—quite the reverse of the claim that euthanasia is commonplace and underground in the UK. In 20,000 cases, I *may* have seen it three times.

[62] In the latest epidemiology on End of Life decisions, 18 per cent of Dutch doctors were concerned about "economic pressures" and the nursing literature has recorded similar experience. In the first Report in 1991, one case was openly cited of a dying patient killed to free the bed (Hendin H (2002) The Dutch Experience. Issues Law Med 17 (3): 223-46; Onwuteaka-Philipsen, B D, van der Heide, A, Koper, D *et al*, "Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995 and 2001", The Lancet 2003; 362: 395-399; The Remelink Report—full text—Dutch Department of Health 1990).

[63] By which I mean ignoring the unreported cases and the escalation of sedative and opiates with the intention of killing—which they may well not do.

[64] It is sobering to know that medications that may kill the recipient as a complication are extremely closely monitored. For example, chemotherapy or radiation, that may harm a third party, let alone kill them, are handled under the strictest regulation. A justification that AD/TK occurs anyway and legislation leads to regulation is utterly specious. If that were so, then sado-masochism (consenting harm to another) and all sorts would be legal.

[65] Justice dictates that appropriate treatment rights are universal.

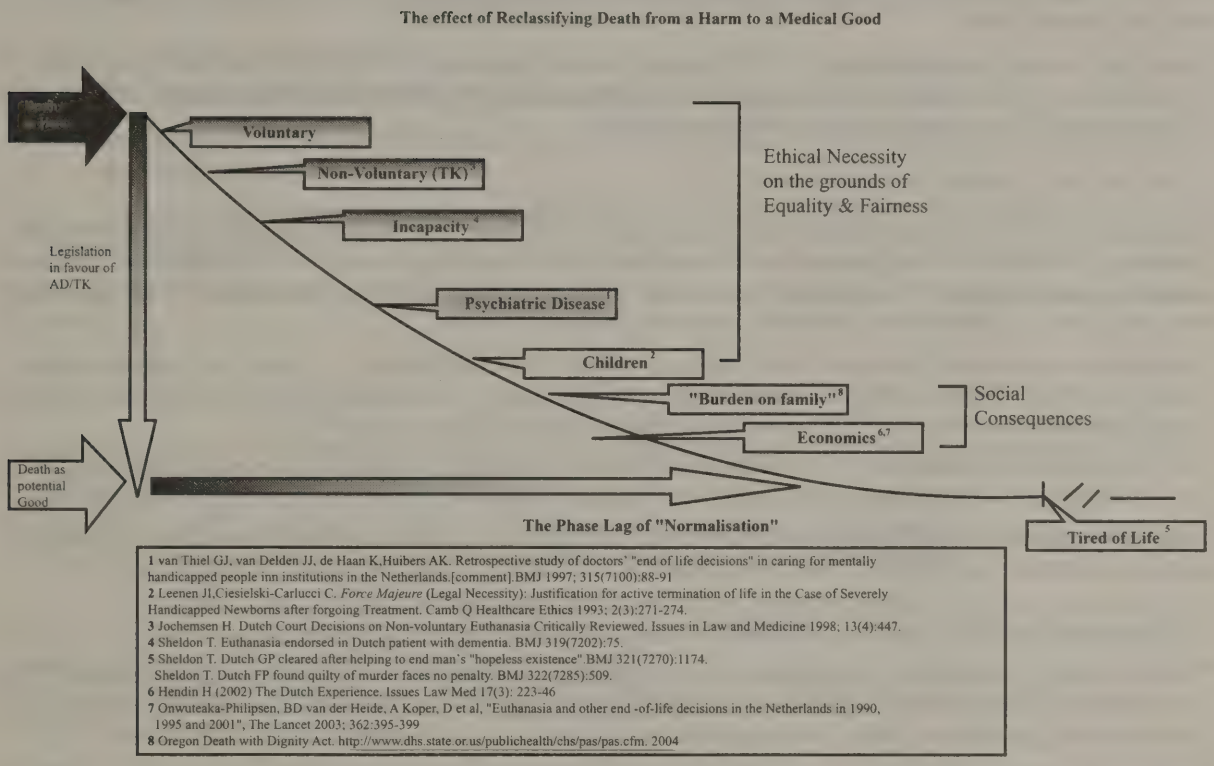
[66] It is of course impossible to diagnose or evaluate suffering: it is simply what a person says it is. However doctors will try to and will then apply the criteria across the board as with any other "diagnosis".

[67] Holland is the only nation at steady state; Oregon cannot answer these questions, as their monitoring does not include death certificate studies or direct questionnaires of doctors' practices outside the law.

[68] That is if killing is the best treatment for the sufferings that come with the capable of humanity in the face of making the incapable expendable.

[69] Hence we see a time lapse for economic factors to have an influence in Holland (note 8). It is also entirely understandable that being better off dead could become an issue as populations age. Interestingly, Oregonians seem to be finding that being a burden has risen from 18 per cent to an average of about 35 per cent in requests for AD over only five years, even though their families insist that they are not. It is hard not to wonder whether patients are feeling subconscious duties to die.

The Figure shows this argument diagrammatically.



To conclude the ethics, looking at autonomy in the round, a tiny minority may have it promoted if their doctors agree, whereas anyone at risk of expressing distress, who is incapable, also runs the risk of TK as a treatment. I am forced, therefore, to think that the protagonists' concern for genuine autonomy is a justification, not their primary motivation. Were it so, then medicine should not be involved and legislation should make the means to die freely available and without prejudice to those wishing to enact this, whilst articulating publicly the risks that this will bring. Equally, I reject argument 2 as being based on false premisses about the profession or a justification of sanctity of life. However, from argument 3 I conclude that on principle, safeguards are not possible. Hence, since the protagonists resist admitting that safeguards are not viable, despite the evidence, they must have other motives or premisses driving their cause[70].

There is nothing wrong with wanting euthanasia because one wants it; what is unacceptable is to pretend that no one will come to harm as a result. Those with overwhelming terminal illness who want to die need help to let go as a promotion of their autonomy—something very different from killing[71]. Where clinicians cannot do this, the answer is training and support, not therapeutic killing.

I come now to some clinical cases.

[70] The Lord Joffe does, however concede that he sees the current Bill as the beginning of an incremental process.

[71] The burden of disease in dying patients is such that the effort that they expend is in staying alive. Helping a person to let go usually involves work to resolve their relational and ontological conflicts. Once done death usually follows in hours or days at most, unless they are holding on for something important. Sadly, in Diane Pretty's case, I suspect it was her legal campaign that kept her going so long.

II. Clinical Cases

The following cases illustrate the key areas in which palliative care engages suffering and particularly the desire for death. I cover sedation, the Double-Effect, which I find almost universally inapplicable, failed suicides and the most important area, facilitating people in their quest to "let go".

A. *Sedation and analgesia*

I reiterate that the literature is clear: in dying patients, the correct use of sedatives and opiates do not shorten life; their disease does.

From my records, approximately 1:1000 patients require significant sedation to gain adequate pain or symptom control for distress; 1 per cent require sedation due to unresolved terminal agitation[72]—they want to be calm and in my experience don't want euthanasia.

1. *An example of uncontrolled pain*[73]

This lady in her 50s had breast cancer and extensive pelvic disease. Consequently, she had severe nerve pain in the legs. She failed on standard analgesic regimes and needed an epidural catheter. This ordinarily produces complete analgesia, but it was only partial successful. There was much distress from conflicts and tensions in her young family. Their future caused her grave concern.

Where pain escalates out of control, the "cycle of suffering" is best broken by a period of unconsciousness. Sedation is then titrated so they are asleep unless awoken to talk. This mitigated her distress sufficiently for useful conversation and the difficulties within the family to be addressed partially.

Once the dying progress began[74], her conscious level deteriorated from disease and her increased desire "to let go". Sedation was reduced progressively and she remained completely comfortable with full pain control[75].

Such management falls well within the current law. Absolutely no legislative change is necessary for adequate pain and symptom management. Its inclusion of this in the Bill is superfluous and an obfuscation.

2. *The demand to be killed and the Double Effect*

This is the most extreme case. A gentleman with lung cancer and brain secondaries demanded euthanasia. The reasons were a complex mix of difficulties within extended family. The day on which he wanted to die was the anniversary of his mother's death. Management was difficult for some months as he refused access.

The family called as an emergency when Fred wielding a knife threatened suicide. I visited with a consultant nurse[76] who removed his wife and children to safety. The patient demanded that I kill him by 6.00 pm or he would kill me. I negotiated that I would sedate him until he died, but not kill him. He calmed down, spoke to his family and, despite explanations by me, stated that I would give him an injection to kill him. He went to bed and I drew up a combination of heroin and sedative[77].

He slept and the family assembled, including his estranged son. The patient woke four hours later, the day's events having been ablated by the sedative. His son helped him to the toilet, following which they talked for over an hour and healed much from the past. Having taken to his bed, Fred began to withdraw and let go. He spoke occasionally, usually to say sorry or "I love you". Infection from his lung cancer killed him three to four days later.

During that time we did a great deal of work with the family to resolve a considerable number of matters. There was full reconciliation and he died very peacefully.

A superficial view might consider this to be Double-Effect. However, controlling his distress with medication quite clearly enabled another series of events to take place, namely the resolution of conflict with the family. Hence, in causal rather than temporal terms, there was absolutely no linkage between the sedation, pain control and his death. The drugs were used to create "Decision Space" free of suffering. This is not Double-Effect.

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[72] These patients are almost without exception those who are referred too late to our services and in whom we have been unable to address underlying fears and anxieties to do with the dying process or what may lie beyond death. (see Higginson *et al*).

[73] All these cases are discussed with permission and are anonymised.

[74] A period that may last days and in some cases weeks.

[75] It is worth saying that, in this context, the doses of opiates and other analgesics can be very large and patients are able to tolerate these with impunity.

[76] After discussion we judged not to use the police.

[77] I have to say that, where clinicians decide to use medication in these circumstances, the nuances of philosophy pale to insignificance. I had to ask myself explicitly the purpose of this intervention. I decided that this was the only measure to restore safety and security to all concerned and I quite explicitly had no intention to kill him and said so to all concerned.

My overwhelming experience confirms that opiates and sedatives in this kind of setting seldom, if ever, cause death. However, an alternative scenario may emerge, namely that medication assists the patient to relax as suffering is relieved; letting-go is then unimpeded by disturbing symptoms or emotional/spiritual suffering. This is not Double-Effect either.

Ironically, despite explanations and discussion, the family concluded that Fred was suffering, the doctor had given him an injection and he had died. Such misinterpretation is commonplace: they saw an assisted death with drugs while, in fact, medication created the space for Fred to resolve matters before he died. They are wholly different things and, in my opinion, the correct ways to promote his autonomy.

Was I to be operating under this Bill,

- — the patient would have died before the emotional processes had been undergone;
- — comprehensive clinical therapeutics[78], psychological support[79] and family work would have been superseded by protocols.
- — the suffering may have been removed, but not resolved and no doubt would have emerged in various of the family's lives.

The Bill would have made management of this case far harder as I doubt that Fred would have tolerated the delays.

3. *Failed suicides*

Suicide in the dying is extremely rare[80]. There may be more who are quite happy for another to take the responsibility, but that is not the same thing.

7-9/~20,000 cases I have managed were attempted suicides, three were successful one of which was "rational"[81]. One was managed in the acute hospital, the other three in the community.

Case 1. Peter had end-stage HIV disease and attempted suicide in a car crash, had multiple fractures and spent his last few months largely in bed. During this time we discussed the reasons for his wishes and explored his personal history and difficulties. Consequently, this patient had no regrets that he had lived. He said when he died—a peaceful and easy experience—how grateful he had been for the opportunity to deal with unfinished business, for he was now able to let go.

In this case it took one to two months to establish sufficient relationship with Peter[82] and it was in the last month of his life that the most fruitful work was done. Were this law to have been enacted I have no doubt that he would have had euthanasia and never had the chance to resolve the pain of his past.

Case 2, Mark was miserable. One night, he took all his morphine and anti-depressants. I had known him for some weeks—insufficient time to do any meaningful psychological work. Suicide and euthanasia had arisen as we discussed his attitude to death and dying[83]. He had stockpiled drugs as he knew the law. Mark's partner called one night when he found him unconscious and breathing very slowly. Mark hated hospital, so I stayed with him for several hours, but did nothing as he would wake eventually. This happened and his medication was converted to injectables. He had little to say and expressed no views on his failure. I confirmed his refusal of further treatment and hospital admission. I had insufficient time to engage his psychological difficulties and he died a few days later fully symptom controlled.

Were this Bill enacted, I expect Mark would have refused any palliative care except for pain control, may well have been considered sad rather than depressed[84] and have been classified as a rational. I doubt he was taking his antidepressants. We rather than he would have taken responsibility for his death.

Case 3. David also had HIV. I was involved by the GP, David's life-long friend. She had been asked to prescribe drugs for euthanasia. She was very distressed, felt completely divided in her loyalties and quite unable rationally to engage the issue.

[78] Sedation *etc* could not have been given because of the effect on capacity.

[79] Fred would have been preoccupied with administration and not sorting the family issues.

[80] (JAMA ref) Given the availability of drugs in very large doses to dying patients and the claims about incidence of unbearable suffering made by others, I find it difficult to conclude that there is a significant part of this population that is interested.

[81] "Rational Suicide" is said to be a decision to kill oneself uninfluenced by mental or emotional disturbance by a patient who is fully competent.

[82] Incidentally, Peter had been referred to me because of his request for euthanasia.

[83] It is a routine part of my practice to cover these areas and discuss the issues explicitly.

[84] I list relevant references on depression and psychological issues at the end of the submission.

I stopped his HIV medications and over three months worked with him, his parents (both psychiatrists) and his partner. His anger took weeks to subside, but reconciliation was complete[85]. He was very grateful for the summer and frequently expressed how foolish it was of him to have wanted suicide.

There is no doubt that David would meet the Bill's criteria for AD/TK. His anger, distress and intelligence would have combined to make the case and he would have refused enquiry or palliative care. It was only that he had no option than to engage his suffering that meant he was able to have such a productive and fruitful time with his parents and partner. Assisted dying would categorically have deprived him of this.

4. *Promoting autonomy: Unimpeding death and assisting dying using classical palliative care, not lethal prescriptions*

This is substantially more common. I draw on three cases from the last three months who wished to die. Futility or hopelessness were the issues, not symptoms. In all such cases I

- Explain that given their burden of disease, energy goes into staying alive: dying is simply letting go of life.
- Take patients through a variety of techniques to discover explicitly what is preventing their death.
- Engaging the factors appropriately to facilitate resolution.

This requires a combination of good symptom control to create a Decision Space in which patients can choose to resolve a matter or to let it go.

- Where there are realistic, unfulfilled tasks, we attempt aggressively to complete them;
- Where the matters of relationship are a problem we engage them; and
- Where the difficulties of facing death *per se*, we engage the individual's spiritual perceptions and beliefs, in terms of their viability and effectiveness, in helping them to find meaning.

Case 1 Stuart had a disfiguring, painful throat cancer; prognosis could have been years[86]. Swallowing was difficult, but he refused artificial feeding, and stated quite clearly that he wished to die. Over the next two weeks we addressed his agenda and taught him how to let go. He had two episodes of distress. During one, his wife was insisting euthanasia was the answer. This discussion ran parallel with work on historical conflicts with his wife. Once resolved all matters settled and he died comfortably within days. At bereavement follow-up, she understands how her feelings were running at the time.

Were the Bill enacted; that night I have little doubt some physicians would have found the pressure overwhelming. I can imagine Stuart being classified as a therapeutic killing, justified because he had previously requested euthanasia and was suffering unbearably[87]. In truth it was a bad night.

Case 2 Gladys had advanced cancer. Her family said she was always "flat". She felt a burden on her family. She was managed in a similar way and let go three to four weeks later[88].

Case 3 Maisie, 90, wanting euthanasia, was referred by her GP who had known her 50 years. She was extremely intelligent and well read. She had pain from arterial disease in her legs and local infection. Her marriage had been very unhappy, her husband alcoholic. She had been struggling with her historical beliefs about eternity and resolved to exclude herself "because I couldn't go through another life like that". Her solution was to ask for euthanasia when the issue was theological. We talked, she then deteriorated rapidly and died comfortably although she needed small amounts of sedation to manage confusion[89]. This whole episode spanned four weeks.

These are typical examples of facilitated autonomy by giving the means to let go. This approach honours and respects the individual far more, allows them to understand their life's journey in a different way and makes it possible for them to exit this world with as little residual baggage as possible. The periods of time are short—weeks not wasted by protocols, paperwork and the like.

This approach respects everybody's autonomy and puts no one at risk. Furthermore, families and loved ones also engage a dying process, which for the majority is extremely unwelcome, but the benefits in bereavement are substantial.

[85] The parents subsequently contacted me for further information on how to handle the psychological issues around death and dying as they had not encountered this before despite being consultant psychiatrists.

[86] These tumours are slow growing and prognosis can be long even with very significant local disease.

[87] I would be amazed if such clinicians would be disciplined. It would be seen as best interest (a medical good) overruling an anomalous law.

[88] Her issues were minor, spiritual and sorted by the chaplain.

[89] It is virtually axiomatic that terminal agitation speaks of unresolved "stuff".

I have at least a dozen patients from the last two years with MND for whom this approach is especially appropriate and effective. A final example for completeness is a woman with motor neurone disease whom I managed a few weeks ago. She was a patient very similar to Diane Pretty. I worked with her until the point of letting go. It took her a fortnight.

Discussion would be incomplete without mentioning those who insist upon euthanasia but also refuse to engage their issues. I have three clearly memorable cases who died having acute treatments and asking for full resuscitation. Two of these patients had HIV disease and one had motor neurone disease.

III. Conclusion

I see no place for legislative change. Provided patients are prepared to take responsibility for themselves and their dying then the outcome is a greatly enhanced autonomy for them, their family and clinicians: dying then becomes an adventure and opportunity to completed their business in the context of the life led with families left with the memory of a powerful and authentic experience of healthy dying. Equally an autonomous person is perfectly free not to engage these things. However, it does not translate automatically into an obligation and duty on us to kill them on demand.

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Memorandum by Professor John Griffiths, Faculty of Law, University of Groningen

Personal information: I was educated in philosophy (Univesity of California, Berkeley) and law (Yale Law School); I worked for two years at the United States Supreme Court (Justice Fortas), and have held positions at the Yale Law School, the University of Ghana Faculty of Law, New York University Law School; since 1977 I hold the chair in Sociology of Law at the Faculty of Law, University of Groningen, the Netherlands. Since the late 1980s my research has focused largely on problems surrounding the regulation of euthanasia and physician-assisted suicide. In this connection, I have conducted and supervised a large number of empirical research projects and have written widely on the law related to euthanasia and the reasons for its (in)effectiveness. My most important publication on the subject in English is *Euthanasia and Law in the Netherlands* (with A Bood and H Weyers; Amsterdam, 1998). The following submission is adapted from an article to appear in E Dahl and D Birnbacher, ed, *Physician Assisted Suicide. Moral, Legal and Social Implications of Giving Death a Helping Hand* (Kluwer, International Library of Law and Ethics in Medicine).

Summary: Unlike the proposed UK bill, euthanasia and physician-assisted suicide (PAS) are treated practically identically in Dutch and Belgian law, and in medical practice there seems to be a clear preference for euthanasia. The reasons for this preference on the part of doctors are not clear, but there are strong reasons of public policy for wanting as much as possible of this sort of medical behavior to take the form of PAS. I will argue that the legislative indifference and its results in practice are undesirable and that the UK bill represents a substantial improvement in this regard.

1. It is important to begin by noting that the difference between the two may not always be very big. Take for example the "suicide machines" that Nitsche and Kevorkian are said to have designed. A doctor attaches a patient intravenously to an apparatus containing a deadly drug. We can certainly wonder whether under such circumstances it makes any difference for our moral evaluation or for the demands of effective legal regulation whether the patient turns the apparatus on by typing instructions into a pre-programmed computer or by asking the doctor to open a valve.

2. For present purposes I assume two archetypical scenarios (which, I suspect, in fact represent most cases in actual practice). In the case of what we call "euthanasia" the doctor injects the patient with a deadly drug. In the case of "PAS" the doctor gives the drug to the patient who swallows it. My question is whether it is desirable that the law should be indifferent between these two scenarios.

3. Two limitations on what I shall have to say should be noted. (1) There are patients who are not capable of performing even the simplest last act required for suicide. For these patients, PAS is not an available choice, and the proposed Bill makes specific provision for them. (2) I shall deal only with that form of euthanasia and PAS that is legal in the Netherlands and Belgium, and is proposed in the Bill, namely when it is done by a doctor.

Current Law in the Netherlands and Belgium

4. Article 293 of the Dutch Criminal Code forbids euthanasia (and thereby makes it a less serious offence than what it otherwise would be, namely murder). Article 294 forbids PAS (which otherwise would not be an offence at all). Euthanasia is a more serious offence than PAS, with a maximum punishment of 12 years as against three for PAS.

5. In the Dutch legalisation discussion there has seldom been any distinction made between euthanasia and PAS: most participants who refer to "euthanasia" mean to include PAS as well.[90] In the case law that brought about the legalisation of both there was no suggestion that there is any difference in legality or in the required "rules of careful practice" that a doctor must abide by. The State Commission proposed in 1985 to legalise them on the same footing. Reports of the Royal Dutch Medical Association (KNMG) until recently made no distinction between the two. The successive legislative proposals and the law enacted in 2001 treat the two in the same way.[91] The observation of Leenen—until his recent death the most prominent Dutch expert in medical law—reflects the Dutch debate very nicely. Despite the fact, he said, that two different articles of the Criminal Code are involved, PAS "performed by a doctor in a situation of serious physical or mental suffering . . . is in essence the same as euthanasia." "There is," he continued," no reason to distinguish between the two."[92]

6. In the last few years there have been sporadic signs of change in the Dutch tendency not to distinguish between euthanasia and PAS.[93] Once in a while a doctor writes an article in a newspaper or elsewhere arguing that in general a patient who wants to die earlier than he otherwise would have done, should take the moral responsibility for the final act himself. The Medical Association, in its most recent policy statement on euthanasia, suggests that where possible PAS should be preferred. So far, however, there has been no indication in the case law or other legal sources that lawyers are inclined to impose any such requirement.

7. Until recently, Belgian law contained nothing more on the subject than an unqualified prohibition of murder (with no lesser offence of euthanasia).[94] PAS was not prohibited at all as far as the Criminal Code was concerned, but the Medical-ethical Code did forbid it for doctors on pain of temporary or permanent suspension from practice. According to Adams some Belgian legal scholars suggested that a doctor who performed PAS might be prosecuted for some other crime (such as failure to assist a person in danger of death). Nevertheless, the situation was one of *de facto* decriminalisation: until the public debate on legalisation of euthanasia got started, a doctor had apparently never been prosecuted either for euthanasia or for PAS.

8. The new Belgian law[95] regulates only "euthanasia". It is defined in the same way as in the Netherlands: "intentional termination of another person's life at his request." It appears from the text of the law that "psychiatric patients" are not excluded. A doctor who performs "euthanasia" does not commit an offence if he complies with rules of careful practice very similar to the Dutch rules.

9. The Belgian law says nothing about PAS. In light of the considerable confusion on the matter that marked the debates in the Belgian Senate (different speakers referring to totally different things when using the term "PAS"), it is unclear whether the statutory term "euthanasia" includes PAS or not. However that may be, it is in any case certain that there are no different indications or rules of careful practice for PAS than those that apply to euthanasia. If there is a difference between the two, it would appear to be that whereas the statute legalises euthanasia, PAS, to the extent it ever was prohibited, still is. There is in any case no question of a legally preferred position for PAS.

The Exceptional Position of the Netherlands and Belgium

10. Just about everywhere in the world where there is any discussion at all of the possibility that a doctor might be permitted, under narrowly specified circumstances, to end the life of a patient at his request, what the proponents have in mind is PAS and not euthanasia. Outside Belgium and the Netherlands, euthanasia is rarely even considered.

11. In the "common-law" countries suicide was traditionally a serious criminal offence. In the course of the last century decriminalisation took place everywhere. In the statutes by which this was accomplished, a new offence of assisting suicide was almost always created. In practically the whole common-law world, the public debate concerns the question whether this relatively new offence should be repealed, or at least limited in its application to doctors.[96]

12. In countries with continental legal systems, suicide has not been an offence for some two centuries (since the Napoleonic codifications). In principle, assistance with a legal act is also legal. In Switzerland there is an institutionalised practice of PAS by laymen (medical ethics being thought to make assistance by a doctor

[90] *See* Griffiths, Bood & Weyers 1998: 111 ff.

[91] *See* Griffiths, Bood & Weyers 1998 for the successive legislative proposals and Weyers 2004 for the history of legal change. The new law is the Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, Stb. 2001, 194, in effect as from 1 April 2002. For a full account of Dutch euthanasia law shortly before the final act of legislative legalisation, see Griffiths, Bood and Weyers 1998.

[92] Leenen 1994: 296.

[93] *See* Griffiths, Bood & Weyers 1998: 112-113.

[94] On the situation in Belgium see Adams 2001: 29-31.

[95] For the text of the law see Kamer van Volksvertegenwoordigers, doc 501488/001.

[96] Cf Otlowski 2000.

impossible). In some countries (France and until recently, at least, Germany) the requirement of helping a person in danger is thought to stand in the way of assistance with suicide.

13. The Netherlands is thus exceptional in two respects. It deviates from the other countries in the continental tradition in that the legislator—in the second half of the 19th century—added to the Criminal Code a specific prohibition of assistance with suicide. And it deviates from the rest of the world in the predominant position that euthanasia occupies in the public debates and in legal development. Belgium, as a result of its new law and despite the uncertainties concerning the legal status of PAS, has come in these respects to resemble the Netherlands.

The Place of PAS in Medical End-of-Life Practice

14. How deviant the Dutch and Belgian situation is becomes even clearer if we look not only at the law but also at medical practice. From the very beginning, Dutch doctors have practised euthanasia far more frequently than PAS. As far as we can tell, the same applies to their Belgian colleagues.

15. In the three years for which we have reliable national statistics, the picture for the Netherlands is as follows:[97]

Euthanasia and PAS, Netherlands, 1990, 1995 and 2001 (percentages of all deaths)

	1990	*1995*	*2002*
euthanasia	1.8%	2.4%	2.5%
PAS	0.3%	0.3%	0.2%

In 2001, of every 12 cases of termination of life by a doctor on request only one was PAS. The imbalance had become rather more pronounced since 1990, when it was seven to one. Similar data are available for Belgium (Flanders) for the year 1998.[98]

16. The annual reports of the Dutch Regional Assessment Committees cover cases that the responsible doctor officially reported (currently about half of all cases). For 1998 through 2001 these reports give the following distribution over euthanasia and PAS:[99]

EUTHANASIA AND PAS, NETHERLANDS, 1998–2001
(PERCENTAGES OF ALL REPORTED CASES)

	euthanasia	*PAS*	*combination*	*all reported cases*
1998 Nov/Dec	91%	8%	1%	349
1999	90%	9%	1%	2,216
2000	88%	10%	2%	2,123
2001	89%	9%	2%	2,054
2002	89%	10%	1%	1,882

As in the national data covering both reported and unreported cases, it appears from the data on reported cases that the share of PAS in all medical termination of life on request is about 10 per cent.[100] There is no indication of any movement in the direction of a greater role for PAS. It is interesting to note that the Assessment Committees give no indication in their annual reports that they are concerned about this situation.

17. These data say a lot, but not everything. To be scrupulous in interpreting them we would have to limit ourselves to cases in which the patient could have performed the final act himself, for it is only in these cases that there is a real choice. As far as I am aware, such data do not exist. If we make the rather crude assumption that patients with less than a week to live are generally not able to perform the final act, whereas if remaining life is longer than that they generally are, then in 1990 there were 920 and in 1995 1,280 cases of euthanasia in which PAS was an available alternative.[101] That is two to three times the number of cases in which PAS in fact occurred.

[97] *Source:* Griffiths, Bood & Weyers 1998: 210; Van der Wal and Van der Maas 2003. A study among ALS-patients gives a similar picture (Veldink *et al*, 2002). One study suggests that among AIDS patients the frequency of assistance with suicide may be rather greater: about half (Bindels and Krol 1996).

[98] *See* Deliens *et al.* 2000: 1808.

[99] *Source:* Regionale Toetsingscommissies Euthanasie 2000–02.

[100] Comparison of the data from the national studies (all cases) with those of the Assessment Committees (reported cases) shows that the ratio of PAS to euthanasia apparently is not correlated with the frequency with which doctors report.

[101] *See* Griffiths, Bood & Weyers 1998: 224–225.

How Can the Preference of Dutch and Belgian Doctors for Euthanasia Be Explained?

18. We do not know why it is that Dutch and Belgian doctors so overwhelmingly prefer euthanasia to PAS, the question never having been seriously addressed in research. There are, however, some suggestive hints in the Dutch literature.

19. One possibility, of course, is that it is not doctors but their patients who choose for euthanasia. However, a doctor who has a preference for PAS could offer only PAS as an option to a patient, or he could try to convince the patient that it is the better choice, or he could simply refuse to perform euthanasia. In short, the ultimate choice lies with the doctor.

20. It has been suggested that at the beginning of the process of legal change in the Netherlands many doctors associated suicide with psychiatric disorder. Since in the view of doctors patients' requests for termination of life have nothing to do with any such disorder, they preferred that form of termination of life free from any such association.[102] This may be a plausible explanation for the early years but it does not explain why the share of PAS is still so low and in fact declining.

21. In the early years of euthanasia practice Dutch doctors were supported in their preference for euthanasia by influential organisations.[103] It was not until 1984 that the Medical Association recognized PAS as a legitimate alternative for euthanasia. Proponents of legal euthanasia, such as the Dutch Association for Voluntary Euthanasia, apparently sought in the early years to avoid any association with psychiatric disorders. But if the position of such organizations was an important influence on doctors, the fact that the organizations concerned long since changed their position should have been reflected in a change in medical practice. Quod non.

22. Another possible explanation for the preference of Dutch doctors for euthanasia is the fact that from the beginning legalisation in the Netherlands was seen as a matter of the empowerment of doctors and not, as in the United States for example, in terms of the rights of patients. Perhaps doctors find it natural, once they have taken a decision that is conceived of as uniquely theirs, that they should carry it out themselves.

23. There may also be reasons of a more practical nature. Euthanasia can be performed with drugs that act very quickly, so that the dying process is over within a few minutes and the duty of the doctor to be present the whole time is less burdensome. The dying process is also more within the doctor's control. On the other hand, one must not forget that in the early years, when current practice achieved institutionalised form, the drug of choice for euthanasia was morphine, whose working is slow and notoriously unpredictable. Any difference between euthanasia and PAS in this respect cannot have been great. Such practical considerations therefore offer no explanation for the emergence of Dutch doctors' preference for euthanasia, at most for its resistance to change.

24. The risks that outside the Netherlands are often associated with PAS might also offer an explanation for the preference for euthanasia. But when proper drugs are used, these risks are in fact small.[104] Furthermore, they are principally relevant in the case of PAS outside the presence of the doctor, something that in the Netherlands is permitted, if at all, only in exceptional circumstances. These supposed risks, too, seem not to explain doctors' preference for euthanasia.

25. In short: it remains a mystery why Dutch (and apparently also Belgian) doctors exhibit such a consistent, long-term, and apparently growing preference for euthanasia over PAS.

Considerations that Would Support a Different Choice

26. Whatever the reasons may be that explain the preference of doctors for euthanasia, these would not seem nearly comparable in weight to the reasons that point in the other direction: that PAS should be the "normal" procedure and euthanasia the exception. Let me mention some of them:

— Legalisation of euthanasia deviates more strongly from the law in other countries and arouses stronger emotional and ethical objections than legalisation of PAS. Even if one does not share the objections, there is something to be said for a "healthy respect for the opinion of mankind", at least when one does not have to offer up any basic principle. To the extent law and practice were to move in the direction of PAS, international opposition would probably lose much of its fervour.

[102] Cf. KNMG 1984.

[103] *See* Weyers 2004: 136–137, 178 n 83; cf Griffiths, Bood & Weyers 1998: 57–58.

[104] *See* Horikx and Admiraal 2000; Oregon Health Division 1999–2002.

— In the case of PAS the patient bears the moral responsibility for actually carrying out his wish. A number of Dutch doctors have pointed out that in the case of a patient who could have done the fatal act himself euthanasia involves a shift of responsibility to the doctor.[105] Whether it is the patient who prefers to pass the moral buck, or the doctor who prefers to keep everything in his own hands, the shift of responsibility is in itself undesirable and imposes a far greater psychological burden on the doctor than in the case of PAS.

— When the patient takes responsibility for carrying out his decision, the seriousness and autonomy of his wish to die are better guaranteed than when all he has to do is ask.

— It appears that it regularly happens in practice that a patient whose doctor has agreed to participate in PAS decides at the last minute not to take the lethal drugs the doctor has supplied. This may be a confirmation of point (3): the patient's wish for death was not as authentic as it appeared. But it may also indicate—and some thoughtful doctors are of this view—that what the patient really sought was control over the situation surrounding his death.[106] Once given that power of control the patient recovered the will to continue struggling for life.

— The transparency of medical behavior and the effectiveness of the control regime are undermined by the presence of a "grey zone" between euthanasia and pain relief. It appears from the Dutch data that a significant part of what is actually euthanasia is—consciously or unconsciously—regarded by the doctor as pain relief and reported as a "natural death", so that the controls applicable to euthanasia do not operate.[107] There is no room for such (self) deception in the case of PAS.[108]

We can conclude from considerations such as these that there are substantial reasons for preferring doctors to choose PAS whenever that is possible. I am not aware of any counter-argument.

27. The simplest and best way to make PAS more attractive whenever it is a real alternative is to give PAS a preferred legal position, and to require a specific justification in the case of a choice for euthanasia. Because it does precisely this, the UK Bill is in my opinion a considerable improvement over the Dutch and Belgian legislation.

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[105] *See* Arentz 2001, Zwaveling 1994. Cf. Griffiths, Bood & Weyers 1998: 112 n 78. According to Van der Wal and Van der Maas (1996: 173) and Benjaminsen (1988), many doctors say they share this view. Such a general attitude apparently has little influence on their behaviour.

[106] *See* Griffiths, Bood and Weyers 1998: 113-114.

[107] *See* Griffiths, Bood and Weyers 1998: 255-256, 271-272.

[108] It might be objected here that it is precisely the greater possibility to report the death of the patient as a "natural" one, thereby eluding the control system, that consciously or unconsciously leads doctors to choose euthanasia. There may well be some truth to this idea, but perhaps not quite as much as one might think at first. The choice between PAS and euthanasia will seldom depend only on a doctor's anticipation of his willingness to report accurately.

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Memorandum by Colin Harte

1. Introduction

1.1 I have been a full-time carer of a severely disabled woman, Alison Davis, since 1989 (having known her from 1987). For the first six of those years (1989–95) Alison had a persistent wish to die, and she had had a persistent wish to die for some years before that (since 1985). Before I started to care for her she had attempted to end her life on several occasions. Some of the attempts were serious, as a result of which she was hospitalised and recovered only because she was treated, against her will, after she lost consciousness. Alison has written her own submission to the Select Committee on behalf of the group No Less Human and I am mentioning her in my submission with her consent. I am thankful that legislation like the Assisted Dying for the Terminally Ill Bill, or the Dutch euthanasia law, did not exist during the period 1985–95. Alison would have qualified for euthanasia, would have requested it, and her wish would have been granted and she would now be dead. Alison is also grateful now that she did not then have the opportunity to choose death. In this submission I will comment on the difficulties that a law allowing euthanasia would pose for family members or carers of terminally ill/disabled people.

1.2 In this submission I shall avoid the euphemism "assisted dying" and use the more appropriate term "euthanasia." By euthanasia I mean an act or an omission which of itself and/or by intention causes death (ie, kills someone) with an aim of ending a life that is regarded as burdensome either for the person concerned or someone else.

1.3 The title of the Assisted Dying for the Terminallly Ill Bill is misleading because good health care (eg, as found in hospices) provides a legitimate assistance in dying which does not involve euthanasia. Also, the definition of "assisted dying" in the Bill includes the situation in which a physician is not in fact "assisting" but is actually "ending the patient's life" (Clause 1.2).

1.4 The Bill is further misleading in claiming that it will "make provision for a person suffering from a terminal illness to receive pain relief medication." In fact, the Bill makes no provision for pain relief medication that is not already available. The inclusion of such a "provision" in the Bill/which is even mentioned in its long title/would seem to serve no purpose but to deceive.

2. The Focus on "Terminal Illness"

2.1 The Assisted Dying for the Terminally Ill Bill [2004] differs from its predecessor, the Patient (Assisted Dying) Bill [2003], insofar as it would allow euthanasia for those who are "terminally ill" but not for those who have a "serious and progressive physical illness." It might be claimed that the 2004 Bill refers to those who are "terminally ill" but not to those generally regarded as "disabled," and thus should not encounter objections from groups run by disabled people who have been particularly opposed to euthanasia. Disability groups would be right to continue to object to the Bill insofar as those "terminally ill" patients to whom it might apply can rightly be regarded as disabled as a result of their illness.

2.2 Because my submission will refer to my association with Alison Davis I think it is important to explain that her situation, whilst more obviously applicable to the 2003 Bill and a law like the current Dutch euthanasia law, is also applicable to the 2004 Bill. In the mid-1980s, it was believed that she did not have long to live. Her physical suffering (intense pain which caused her to lose consciousness and vision for long periods, difficulty breathing, etc) was such that I certainly did not think she could have long to live, and this was also medical opinion. Medicine is not an exact science, and it causes little surprise to hear of individuals given two months to live with a terminal illness, living for a further two years.[109] I was called to the bedside of a dying friend in December 2002; she is still alive. The concept of "terminally ill" is vague and there is, of course, no way of knowing for how long patients might have lived if they had not been killed under an Assisted Dying type law. The 2004 Bill does not say how close to dying a patient must be to qualify for euthanasia—and of course *this is a judgment that is impossible to make;* the Bill merely says that the patient's illness "must be likely to result in the patient's death within a few months at most." The word "likely" is as nebulous as the whole criteria for allowing euthanasia under the 2004 Bill. Doctors who thought from 1985 that Alison was "likely" to die in a few months would not have been proven wrong if Alison had been granted euthanasia (as she wanted) at that time. The same applies to anyone else killed under a euthanasia law. If the patient is killed the doctors can never be proven wrong. This makes Alison's story particularly pertinent to discussions about euthanasia.

2.3 Although the 2004 Bill refers to the "terminally ill" and not to those with a "serious and progressive physical illness," a law allowing euthanasia for the former will, as a matter of logic, soon be changed to allow (or, in spite of the so-called "strict safeguards", will be interpreted in practice as allowing) it for the latter. The 2004 Bill is clearly a product of the Voluntary Euthanasia Society's carefully orchestrated campaign in recent years, by which it has abandoned the public expression of some of its policies not because they are deemed wrong in principle, but because they seem politically inexpedient (notably, in view of the opposition of disability-rights groups to euthanasia; see 2.1 above). It would seem that the promoters of the 2004 Bill are not aiming to allow euthanasia for all the people they believe should qualify for it. They are, rather, aiming to establish as *a principle* the legality of euthanasia, but the focus on the terminally ill is in fact unprincipled. Barbara Smoker, Former Chair of the VES, made the VES's position clear in its own newsletter, emphasizing that those who are not terminally ill may, in the VES' view, be better qualified for euthanasia.

> Why should the question of terminality be regarded as a relevant criterion at all? Indeed, provided pain is adequately controlled, the terminally ill patient is less likely to need euthanasia than someone whose equally distressing illness or disability is not terminal, since the latter could face many years of suffering. The two most important criteria are surely the intolerable nature of the condition and its incurability/the proper question being whether an intolerable condition is apparently incurable, not whether it is terminal.[110]

Euthanasia of those who are terminally ill may result in the loss of days, weeks, months or even years that could have been spent purposefully in spite of/or maybe because of/the difficulties faced by the individual.[111] I am as opposed to euthanasia of those who are terminally ill as I am to euthanasia of disabled people who are not terminally ill. Although the Bill may appear to affect only the former, I believe it will inevitably also affect the latter.

3. The Dynamics of a Change in the Law on Euthanasia

3.1 I would like the Committee to consider how a change in the law to allow euthanasia will inevitably influence an individual's thoughts about ending his or her life, and how the role of family members and carers (as well as others involved like nurses and doctors) would inevitably change if the law were to allow euthanasia.

3.2 In 1989, when Alison wanted to die and would have requested euthanasia were it available, I was assisted by the knowledge that the law prohibited it. The legal prohibition demonstrated that a higher value was attached to Alison's life than to her death. If euthanasia is not an option, those associated with someone who wants to die are able to act with the certainty that there is a presumption in favour of life, and to encourage the person who wants to die to find a purpose, meaning and value to their life.

3.3 If euthanasia were an option, carers, family members and others would live under a constant uncertainty as to what is the best option for someone wanting to die. Instead of being able to assure the person considering euthanasia that their life does have a purpose, meaning and value, there would be an uncertainty as to whether euthanasia would or would not be a better option. Indeed, the encouragement that I gave to Alison over many

[109] *See*, for example, the obituary of Laura Branigan in *The Times* (2 September 2004).

[110] Barbara Smoker, "Remember the Non-Terminally Ill and the Disabled," *Voluntary Euthanasia Society Newsletter* (September 1991).

[111] This is not to say that euthanasia is any more acceptable if the person is apparently unconscious and thought to have no awareness of or purpose in being alive.

years—which eventually enabled her to see that her life had a purpose and value—would be regarded as the most intolerable cruelty in a situation where legal euthanasia would allow her to be "put out of her misery."

3.4 If the Assisted Dying for the Terminally Ill Bill had been enacted in the late 1980s Alison would have qualified for euthanasia. The existence of such legislation would mean that people like Alison were "right to choose death," whereas the only way of encouraging someone to positively re-evaluate their life—as Alison did—is by convincing them that their life does in fact have a value and purpose. And the chances of doing this are greatly diminished if the law is simultaneously telling them that their life does not have a value and purpose—and that their situation is such that not only would they be "right to choose death" but that the means to be killed will be provided. Euthanasia legislation betrays vulnerable people insofar as it reinforces negative attitudes towards their life and facilitates their ending of it.

3.5 Alison has written about her personal experience in her submission (on behalf of No Less Human) to the Committee. In short, she wanted to die between 1985 and 1995. Between 1985 and 1989 she made several serious attempts at ending her life. Between 1990 and 1995 she wanted to die—she said she would go to bed every night hoping not to wake up in the morning but no longer attempted to end her life. During this period she was able to discern ethical objections to euthanasia even though she did not want to live herself. In August 1995 I accompanied her to visit a small project set up to care for 35 disabled children in India. On the night we left the project, Alison said to me "I think I want to live" and noted that it was the first time she had had such a thought for 10 years. She had "fallen in love" with all the disabled children she had met and wanted to do something to help them. She founded a charity Enable (Working in India) [www.enable-india.org.uk] which has grown considerably and now supports 350 disabled children, most of them in residential centres built by the charity. Many of these children owe their present happiness and future good prospects to the fact that Alison was not killed under a euthanasia law in the 1980s. Since 1995, Alison has continued to endure much suffering—in some respects it is greater and she is becoming increasingly less able. What has changed is an appreciation of her own life, and an awareness that she can make a difference to others.

3.6 Although Alison's experience is particularly dramatic, I am familiar with other instances in which people suffering, near the end of their lives, were glad that a choice for death—which might have been made were euthanasia available—had not been made. A friend's wife died of cancer a few years ago. After her death he told me that on several occasions during the last year of her life she had said she could "no longer go on." Yet, at several subsequent stages she would say, "I'm glad I'm still here." If there were a euthanasia law carers (including family members, nurses, etc) would be put under enormous pressure if they heard patients saying they can "no longer go on." As I mentioned earlier, it could be regarded as an intolerable cruelty for them to encourage the person to persevere and, if the law allowed euthanasia, carers might feel obliged to give weight to the patient's expressions in favour of death and see the path towards euthanasia as inevitable. This would in turn reinforce the suffering person's view that death was an appropriate—desirable, even "sensible"—option.

3.7 In fact, suffering people sometimes need the freedom to say that their life is unbearable, that they cannot go on, that they would prefer death, etc—and to know that they will not be taken at their word. During the period in the 1990s when Alison would not have chosen euthanasia even though she persistently wanted to die, she would say such things. She has frequently expressed her fear that if the law did allow euthanasia she would not have the liberty of saying such things because, if she did, she might be taken at her word. The dynamic of end-of-life decisions is such that if euthanasia were legalized, terminally ill people who might say such things—as they do now, *more as a cry for help than with the expectation of being taken at their word*—would find that family members and carers might believe that they were inevitably heading down the path towards choosing euthanasia, and the response by carers who anticipate what seems inevitable would in turn further influence the suffering person to choose euthanasia.

3.8 In short, if the law were to change and allow euthanasia it would not be a simple matter of enabling "choices" to be made. The factors involved in choosing euthanasia are complex, and the very existence of a law allowing euthanasia would tip the balance in favour of decisions to end life. If euthanasia is not prohibited by law it will be regarded as a legitimate—and hence acceptable and good—choice. A change in the law inevitably means that being killed is regarded as a legitimate option for suffering people, and this entails that the continuation of life for the suffering person is not regarded as having a value such that he or she should be protected from lethal harm. Essentially, euthanasia laws indicate that a negative value is attrributed to suffering people and this seems to me—as someone who has a long experience of being with someone who attached no value to her own life—as the ultimate betrayal of suffering people.

4. A Particular Objection to Voluntary Euthanasia

4.1 Some people have objected to the legalisation of voluntary euthanasia not because they object to it in principle, but because they believe it will inevitably lead to involuntary euthanasia which they find objectionable. I believe they are right to believe it will lead to involuntary euthanasia; the so-called "strict safeguards" in place in Holland have been revealed to be cosmetic and it is widely accepted that non-voluntary and involuntary euthanasia takes place there. I believe it is a matter of logic that voluntary euthanasia will always lead to non-voluntary euthanasia,[112] because if voluntary euthanasia is allowed it means that this is regarded as a legitimate and good option. This being so, medical practitioners will inevitably apply this option to patients who have never requested it: the laws of logic would compel them to apply it. This submission has, however, focused on *voluntary* euthanasia. Although I do not think it is possible to say that one form of euthanasia is "worse" than another, I think there are particular objections to *voluntary* euthanasia.

4.2 The particular objection to *voluntary* euthanasia is that it betrays suffering people who believe death is preferable to life. The proper response to those who want to end their life is to deter them and to present a positive view of life. This is what ordinarily happens with able-bodied people who want to die, and the work of the Samaritans is well known and respected in this regard. With respect to the terminally ill or disabled who want to die a different—very negative—judgment is made about the value of their life.

4.3 Unless voluntary euthanasia were to be made available for anyone who requested it—irrespective of medical condition—then any law allowing it will ultimately be based not on "choice" but on a negative value of life with a terminal illness or disability. The fact is, however, that whereas some people with a terminal illness or disability may want to die, others may value their lives and not want to die. This shows that the mere existence of terminal illness or disability should not be regarded as an indicator that death is preferable and that causing death is legitimate. Thus suicide/assisted dying/euthanasia for those who are terminally ill or disabled should not be regarded as distinct from the question of suicide generally. The problem to be faced is that some people who are terminally ill (or disabled) have lives that they perceive as lacking meaning, purpose or value. Just as there is a public policy against suicide for able-bodied people—as indicated by unanimous support for the work of the Samarians—likewise there should continue to be a public policy, upheld by the law, against suicide/euthanasia for those who are terminally ill or disabled.

5. Conclusion

5.1 In this submission I have generally avoided arguments that I believe are likely to be found in other submissions. I have tried to indicate that a law allowing euthanasia will inevitably undermine the value attached to the lives of those deemed to qualify for it. This submission is written after many years' experience of the very real difficulty of trying to support someone who desperately wanted to die. I understand why euthanasia may seem attractive, but believe support for euthanasia involves a false compassion that reinforces the negativity felt by those who feel life serves no more purpose. Given that not all terminally ill or disabled people believe the continuation of life serves no purpose, it is more appropriate to try to solve the problem by trying to foster a better appreciation of life itself. A law that allows people to be killed—even if it is at their request and with their consent—as a means of overcoming their problems with living is not only inappropriate; it is ultimately a betrayal of the truth that their life has a value. The enactment of the Assisted Dying Bill would be a betrayal of those who would avail themselves of what it allows.

5.2 I urge the Committee to reject the Assisted Dying bill.

2 September 2004

Memorandum by Raymond Hoffenberg MD PhD FRCP

I am a retired physician and from 1983 to 1989 was President of the Royal College of Physicians of London. I have had a longstanding interest in medical ethics, was President of the Institute of Medical Ethics and spent two years as Visiting Professor of Medical Ethics in the University of Queensland. My views on the subject of assisted dying have developed after witnessing many deaths in over 40 years of clinical practice and war service in World War II in North Africa and Italy.

[112] In fact, the UK law has started with the legalization—in case law—of non-voluntary euthanasia. The *Bland* judgment (1993) that food and fluids need not be given to Tony Bland (who, with continued sustenance, was expected to live for about 30 years) is an example of non-voluntary euthanasia by omission. Since then other people in a persistent non-responsive state have been similarly killed with judicial approval. At the root of all decisions about euthanasia—whether voluntary or non-voluntary—is a view that some lives need not be, or should not be, protected. Instead of further legalizing euthanasia, I recommend that Parliament overturn the *Bland* judgment and ensure that those who are most vulnerable are granted the protection of the law to which all should be entitled.

In my submission I have considered possible objections to the practice of assisting those who are dying (as defined in section 1(2) of the Bill) to achieve an "easy, gentle and placid death"—a phrase used by William Munk, Harveian Librarian of the Royal College from 1857 to 1898, in a monograph on euthanasia published in 1887. Where possible, I have tried to respond to these objections.

Objections to Assisted Dying and My Responses

Objection 1

1. Adopting such means to end the patient's life should not be necessary, as modern therapy can always relieve physical pain, and the hospice approach is able to provide the emotional, social and spiritual care that characterises a good death.

Response

2. Experienced terminal care specialists admit there is a core of patients whose pain and suffering cannot be relieved except by using extremely large doses of drugs that induce states of coma or accelerate death. Dame Cicely Saunders, the distinguished hospice specialist, estimated that pain could not be controlled in about 2 per cent of dying hospice patients (personal communication). Other experts estimate that not more than 95–98 per cent of pain in terminally ill patients can be relieved. These figures appear to be at the top end of achievement and do not reflect what patients themselves say. In surveys of hospice patients who were asked about their pain level shortly before death, 5–35 per cent rated their pain as "severe" or "unbearable"; 25 per cent said their shortness of breath was "unbearable". Even in the best of hands the figures for unrelieved pain are not insubstantial. Other symptoms such as nausea and vomiting or severe itch can also be difficult to control.

3. Additionally, to many patients loss of capability and independence and/or the indignity of losing control of bodily functions, including sphincters, is more frightening and upsetting than the prospect of pain; these problems are not easily palliated. (As an extreme example I would refer to the case of Mrs Lilian Boyes, a dying patient to whom Dr Nigel Cox administered a fatal dose of intravenous potassium chloride, an act that brought him before the General Medical Council. She was in extreme pain unresponsive to massive doses of morphine, possibly due to the phenomenon of paradoxical pain, she had ulcers and abscesses and gangrene that extended through her rectum into bone; she was doubly incontinent and blind. Even if it had been possible to control her pain, her condition was so distressing that she and her two loving sons begged Dr Cox to put her out of her misery).

4. The reality of the situation is that *a majority of dying patients do not have access to optimal terminal care*. Richard Smith, retiring editor of the British Medical Journal, has written "For the minority who die under the care of palliative teams it is probably good, but there is a suspicion that for the majority who die in acute hospitals or nursing homes the experience is bad". For many of those who die at home it is almost certainly worse.

Objection 2

5. Knowledge that a doctor practises "euthanasia" might undermine the trust that patients have in doctors. They might be fearful of what will be done to them in the last illness.

Response

6. Evidence from surveys carried out in places in which euthanasia is permitted shows that this has not happened. On the contrary, in the Netherlands the percentage of people in favour of continuing the practice has increased steadily over the years. In Britain the number in favour of euthanasia rose from about 50 per cent in the 1960s to about 80 per cent after the Cox and Bland cases in the 1990s, suggesting that the public actually approved of the role of doctors in assisted dying. Surveys of elderly people in Australia confirm this view.

Objection 3

7. Vulnerable members of society will be placed at risk, eg the disabled, the elderly and ethnic or other minorities. A voluntary request for assistance in dying will be replaced by involuntary disposal of unwanted people. Various forms of pressure might be applied to people who want to live, especially the elderly who might be induced to request early death by uncaring members of the family or others.

Response

8. In a civilised society it is highly unlikely that a doctor, other than a pervert or a criminal (Shipman), would acquiesce in the killing of individuals or groups, simply to get rid of them.

9. It is probably impossible completely to eliminate inducements or pressure but the safeguards outlined in the Bill, if followed meticulously, should all but do so. (There is an analogy here in the transplantation field in which free voluntary consent to organ donation is regarded as critical, but undue pressure or coercion is equally hard to eliminate, except through the exercise of close scrutiny and maximal care).

10. This objection exploits the "slippery slope" argument. The flaw in the argument is the following: If practice A (acceding to voluntary requests) is accepted or desired, but practice B (involuntary disposal of people) is not, it makes no sense to ban A simply to prevent B. The right action is to retain A and outlaw B, imposing stringent scrutiny and appropriate punishment for those who transgress the boundary.

Objection 4

11. There is a risk of mistakes in diagnosis or prognosis. There are occasional examples of patients believed to be terminally ill who then recover and return to normal life.

Response

12. It is impossible completely to exclude the possibility of medical error. The likelihood of error would be greatly reduced by the provisions of the Bill, which require confirmation of the diagnosis and prognosis by another physician and a specialist in palliative care. Close observation through the 14 day period should help to minimise the chance of error. In contemplating the possibility of assisted dying doctors could be expected to exercise even greater care to avoid errors.

Objection 5

13. It may be difficult to determine the mental competence of the individual, on which the validity of the request for assistance is dependent. It is known that this might fluctuate in patients with a terminal illness.

Response

14. Competence has to be attested formally by two doctors, a solicitor and the witness. In addition, in most cases there will be family members who can provide information about the mental state of the patient. If there is any doubt on the part of any of these individuals, a psychiatric referral is mandatory.

Further comments

15. In present day medical ethics paramount importance is accorded to the concept of patient autonomy. Competent patients may decide whether or not to accept treatment, and may reject it even if it is thought to be lifesaving. They have power to make decisions about all aspects of their care but not to demand treatment that is regarded by their doctors as harmful or valueless. Presumably, it is under this rubric that patients with terminal illness are denied assistance in dying. They have the right, if they wish, to forgo all treatment including the ingestion of food and water and so to die from dehydration and inanition. Thus, they may elect to die a slow and distressing death but, having made the decision to end their lives, they are denied the means to achieve one that is quicker and more expeditious. Knowing that they are suffering from a terminal illness, they are denied autonomy—the right to choose how and when they would like to die.

16. The provision of the means to end their own lives or the knowledge that their wish to do so will be carried out at a time of their choosing, if their suffering becomes intolerable, can be a great comfort to those who fear the dying process more than death itself. Experience shows that patients who are given the means to end their lives frequently do not do so, but they are reassured by the knowledge that they have the means to do so if necessary.

17. It is usually agreed that there is very little ethical (as opposed to legal) distinction between allowing patients to die by withholding or withdrawing treatment and taking a more active step to end their lives. In all cases the intent is the same and the outcome is the same; only the means of achieving the end is different. Following the Bland case, the House of Lords gave consent in certain circumstances for the withdrawal of food and water from patients in a persistent vegetative state. Death follows about 10 days after withdrawal. During this time the relatives have to watch the slow inexorable extinction of life and the nursing staff have to wash, turn, toilet and generally tend what they know to be an incipient corpse. Would it not be more humane for the family and the nursing staff to expedite the process of dying?

18. There is little doubt that many doctors—good caring doctors—do assist the process of dying. They do so under the guise of the double effect principle—using large doses of a drug in order to relieve symptoms in the knowledge that this might shorten life. In many cases, I suspect, there is an implicit intent to end the patient's misery by doing so. If this intent were overt, they would expose themselves to serious legal and professional condemnation. Had Dr Cox been less ingenuous he might have chosen some other substance that would have hastened death and pleaded that he had acted under the principle of double effect without making his true intent known. A decision to allow assisted dying as outlined in the Bill would obviate a moral and legal contrivance, behind which many doctors take shelter.

19. It is clear from many studies that doctors and other health professionals have little comprehension of the real views of the public with regard to end-of-life decisions. In a Queensland survey, in which I took part some year ago:

(i) 57 per cent of general practitioners believed that patients would prefer to leave such decisions to their doctor; this view was held by only 34 per cent of the community;

(ii) 84 per cent of doctors felt that patients do not like to think about death and dying; only 31 per cent of the community shared this view;

(iii) 62 per cent of patients were in favour of assisted dying compared to 30 per cent of doctors,

(iv) 65 per cent of patients felt the law should be changed to allow the process.

I suspect that a British public would respond in a similar way.

20. I appreciate that many people object to assisted dying on religious grounds. It stands to reason that there should be a "conscience clause" that permits doctors who have this belief to recuse themselves. No doctor should be obliged to carry out any measure that is contrary to a firmly held belief or principle.

August 2004

Memorandum by Professor Emily Jackson, Chair of Medical Law, Queen Mary, University of London

1. Introduction

The absolute prohibition on euthanasia coexists with doctors' extensive involvement in shortening their patients' lives.

Why does the line between lawful and unlawful life-shortening practices lie where it does?

— line only makes sense if we ignore the perspective of the individual patient.

— at odds with patient-centred development of medical law.

2. Reasons for Proscribing Euthanasia

(a) *Euthanasia is intrinsically wrong*

I Sanctity of Human Life

(i) Religious belief that life is not ours to dispose of as we please,

BUT this cannot be the basis of public policy in a secular society.

(ii) Some argue it is illegitimate to make qualitative judgements about whether a life is worth living

BUT doctors already make this sort of judgement:

— doctrine of double effect;

— for PVS patients, eg Bland;

— *R v Cambridge DHA ex p B* [1995] 1 WLR 898 Sir Thomas Bingham:

> "I have no doubt that in a perfect world any treatment which a patient, or a patient's family, sought would be provided if doctors were willing to give it, no matter how much it cost, *particularly when a life was potentially at stake.* It would however, in my view, be shutting one's eyes to the real world if the court were to proceed on the basis that we do live in such a world."
>
> (my emphasis.)

II Act/omission distinction

— Is killing always worse than letting die?

  — Instead of a binary division between acts and omissions, it makes more sense to think in terms of a spectrum.

  — Withdrawing treatment lies in the middle of the spectrum. Depending on the context, it could be either an *act* (eg a malicious interloper) or an *omission* (eg *Bland*).

— Morally relevant fact is whether surrounding circumstances justify treatment withdrawal, not whether its an act or an omission.

— Act/omission distinction adds a redundant layer of sophistry to moral reasoning:

ie we currently say:

the competent patient has refused treatment

— *therefore* treatment withdrawal is an omission,

— *therefore* it is morally permissible,

clearer to say:

the competent patient has refused treatment

— *therefore* treatment withdrawal is morally permissible.

— If withdrawing life support is an omission, how could there be a conscientious objection to "omitting to act?" Yet:

Ms B v An NHS Trust [2002] 2 All ER 449. Dame Elizabeth Butler-Sloss P:

"[Dr C] did not feel able to agree with simply switching off Ms B's ventilation. She would not have been able to do it. She felt she was being asked to kill Ms B."

(b) *Regulatory difficulties*

I Ensuring request is voluntary and preventing abuse

(i) Patients are very ill, judgement may be distorted by depression.

(ii) No scope for correcting decisions based upon a mistaken diagnosis of competence or terminal illness.

(iii) Principle of patient confidentiality makes it difficult to scrutinise oral discussions to ensure requests were informed and voluntary.

(iv) Patients might be pressurised into requesting euthanasia because they perceive themselves to be a burden.

BUT we already allow patients to make life and death decisions, when these considerations may be even more compelling:

Re MB 38 BMLR 175 Butler Sloss LJ:

"A mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death."

Common practices, such as withholding life-prolonging treatment without consent, pose a greater risk than euthanasia to vulnerable individuals.

A carefully regulated system would offer much more effective protection than a blanket ban, which simply pushes the practice underground.

II Slippery Slope

ie difficult/impossible to draw a line between acceptable and unacceptable practices.

— Empirical claim? BUT seldom proved/refuted by the evidence.

— Blanket ban is not necessarily the best response to slippery slope concerns, regulatory safeguards might offer more protection to vulnerable patients.

— Risk that a blanket ban drives the practice underground.

(c) *Protecting the medical profession*

- Intrinsically good for doctors to cultivate a virtue based upon adherence to a strict ethical code.
- Instrumentally good because it fosters patient trust and confidence.

BUT doctors *do* routinely shorten our lives—purely symbolic/linguistic resonance of killing?

- Euthanasia's prohibition is principally directed to preserving this symbolic moral ideal about the proper limits of medical power.

3. Ignoring the Patient's Perspective

Can only distinguish lawful/unlawful life-shortening practices from the doctor's perspective:

- From the patient's perspective, the line drawn between lawful and unlawful life-shortening practices makes very little sense.
- Clinicians prefer methods of shortening life that are more like letting die and less like killing. However, from the patient's perspective, a painful, protracted death is self-evidently worse than a quick, painless one.
- From the patient's perspective, it seems arbitrary that those on life support can insist upon compliance with their requests for withdrawal, while those who are terminally ill but not dependent on machines cannot receive any assistance to die.
- None of the lawful means of ending patients' lives promote the sort of death that most of us would prefer (that is, to die at home in the presence of someone we love).

4. An Absolute Prohibition

- Unlike other ethical principles (such as prohibition on sexual contact with patients and duty to respect confidentiality), there are no exceptions to the prohibition on doctors helping their patients to die, however compelling the circumstances.
- Better to prevent euthanasia for vulnerable patients and to allow it for non-vulnerable patients:
  - We believe that we have the requisite certainty to draw this line for treatment refusals.
  - Whether or not we can tell if a patient is vulnerable does not depend upon whether they want active or passive assistance with dying.
- We can only defend an absolute prohibition on euthanasia if we ignore the needs of a small sub-set of patients for whom it may represent the only way to relieve pain or distress.

A refusal to accept that there are circumstances which would justify making an exception from a general rule against active euthanasia does not take seriously enough the perspective of a competent patient for whom life has become unbearable.

Whose Death is it Anyway: Euthanasia and the Medical Profession

A significant proportion of all deaths are now preceded by a decision taken by a doctor which, when acted upon, will end the patient's life. The purpose of this paper is to investigate why we continue to forbid the medical profession from doing this in the most humane and painless way, namely by administering a single lethal injection. I shall argue that the distinction that the law draws between lawful and unlawful life-shortening practices ignores the perspective of the individual patient. In doing so, the current legal position on euthanasia represents an extraordinary exception to the patient-centred development of medical law over the past 50 years.

There are several stages to my argument. First I critically evaluate the conventional justifications for an absolute prohibition on euthanasia. I argue that euthanasia is not always intrinsically wrong, and that regulatory difficulties do not necessarily pose an insuperable obstacle to legalisation. I suggest that we prohibit euthanasia only in order to protect an abstract idea about the proper role of the medical profession. Next, I contrast the lawful and the unlawful ways in which doctors' decisions may shorten their patients' lives, and argue that these can be differentiated only if we refuse to take into account the plight of individual patients. I then consider the absolute quality of the ban on active euthanasia and suggest that the law's refusal to admit any exceptions to a general rule against killing reveals its inability to respond to individual patients' needs.

1. The Reasons for Proscribing Euthanasia

(a) *Arguments from euthanasia's intrinsic wrongness*

(i) The sanctity of human life:

Some commentators have argued that legalisation of euthanasia/assisted suicide would be incompatible with the principle that all human life is intrinsically valuable.[113] There are two strands to this objection to euthanasia. First, there is the religious belief that life is not ours to dispose of as we please. Secondly, some people believe euthanasia involves making a quality of life judgment that is irreconcilable with the principle that all lives are of equal value.[114]

Neither of these arguments is persuasive. In a culturally diverse society, there is no justification for using religion to restrict the choices available to others.[115] The belief that God alone should decide the moment of an individual's death cannot be the foundation of public policy. It could also be argued that God's monopoly on determining the moment of death has already been substantially undermined by routine practices such as the withdrawal of life-support.

The idea that euthanasia involves unacceptable qualitative judgments about whether a life is worth living is unconvincing, since we already allow competent adult patients to make this sort of judgment by refusing life-sustaining medical treatment. In some cases, doctors must positively remove the equipment that keeps the patient alive, and thus are effectively under a duty to act deliberately to hasten death, even where the patient is likely to make a complete recovery, and wants to refuse life-prolonging treatment for illogical reasons, or for no reason at all.[116]

Doctors are allowed to administer potentially lethal doses of painkilling drugs by virtue of the doctrine of double effect. According to the doctrine, a doctor who intends a good consequence—relieving pain—is not guilty of murder just because she foresees, but does not intend, a bad consequence—ie death.[117] But in the context of palliative care, when a doctor foresees that the dose of analgesic drugs which she is about to give is going to cause death, she must have reached the conclusion that death would be an acceptable outcome. Even if we accept that death is not the principal purpose, she must have decided that the patient's interest in pain relief now outweighs her interest in continued life. It is difficult to see how this decision can be made without taking into account the patient's quality of life.

When life-prolonging treatment is removed from incompetent patients, the judgment that continued life has ceased to be a benefit to the patient is generally made by a third party. The House of Lords decision in *Airedale NHS Trust v Bland*[118] confirmed that life support could be withdrawn from patients in a persistent vegetative state (PVS) because it is not in their best interests to have their lives prolonged, but once a patient has irrevocably lost the capacity for consciousness, it is a matter of complete indifference to him whether treatment is continued or withdrawn. Such a decision cannot be made without imposing *our* judgment about whether a permanently insensate life is worth living,[119] and this inescapably involves making a quality of life judgment.

Adherents of the "sanctity of life" argument should also be troubled decisions of "medical futility". From the patient's perspective, treatment that has a one in 20 chance of curing them is not necessarily futile, rather it may represent their only chance of postponing death. Yet the courts do not condemn doctors who withhold potentially life-saving treatment from patients who want to go on living for as long as possible. Such decisions are believed to lie within the proper scope of medical discretion.

(ii) *The act/omission distinction:*

One possible justification for distinguishing between euthanasia and treatment withdrawal is the distinction between acts and omissions, or between killing and letting die. Instead of a binary division between acts and omissions, I suggest that it makes more sense to think in terms of a spectrum. Towards either end of this continuum might lie cases such as shooting someone at one end, and failing to give money to charity at the other; but in the middle, the line between "doing" and "not doing" becomes much less clear.[120]

Treatment withdrawal, which indubitably involves doctors doing something, is a good example of conduct

[113] L Gormally "Euthanasia and Assisted Suicide: Seven reasons why they should not be legalised" in D Dickenson, M Johnson, J S Katz (eds) *Death, Dying and Bereavement* 2nd ed. (London, Sage, 2000) 286–90.

[114] J Keown *Euthanasia, Ethics and Public Policy: An Argument against Legalisation,* (Cambridge UP, 2002) 244.

[115] M Otlowski *Voluntary Euthanasia and the Common Law* (Oxford UP, 2000) 216.

[116] See, for example, the statements of all three judges in the Court of Appeal in Re T (*Adult: Refusal of treatment*) [1993] Fam 95, and of Butler Sloss LJ in Re MB (*An Adult: Medical Treatment*) [1997] 2 FLR 426.

[117] For a defence of the doctrine of double effect, see J. Keown *supra* n 4, 18–29.

[118] [1993] AC 789.

[119] R Dresser "Missing Persons: Legal Perceptions of Incompetent Patients" (1994) 46 *Rutgers Law Review* 609, 662.

[120] A P Simester "Why Omissions are Special" (1995) 1 *Legal Theory* 311–35.

which lies on the boundary between acts and omissions, because it could easily be described as an action. It is by taking into account the surrounding circumstances, and not by labelling what the doctor does as an omission, that we can ascertain whether her conduct is acceptable. The morally relevant fact is not whether what the doctor does is an omission or an action, but rather whether the background against which the decision has been taken justifies the doctor's conclusion that life, in these circumstances, should not be artificially prolonged.

Evidence that withdrawing life support might be inappropriately categorised as an omission comes from consideration of conscientious objection. Doctors whose consciences prompt them to refuse to participate in the withdrawal of life-prolonging treatment are unwilling to *act* deliberately to cause their patients' deaths. This was the perspective of the treating clinicians in *Re B (adult: refusal of medical treatment)*.[121] Dame Elizabeth Butler-Sloss P explained that clinicians

> could not, however, bring themselves to contemplate that they should be part of bringing Ms B's life to an end by the dramatic *step* of turning off the ventilator. (My emphasis).

(b) *Arguments from regulatory obstacles*

(i) *Problems in ensuring the voluntariness of requests:*

For a number of reasons, it has been suggested that ensuring requests for assisted death are made voluntarily represents an insuperable obstacle to legalisation. First, because it would be hard to guarantee that a patient's desire to die was genuine—and not, for example, a symptom of treatable depression—some argue that we should not comply with any patient's request for euthanasia.[122] Secondly, given the finality of euthanasia, opponents of legalisation have argued that we could never be sufficiently certain that a person's request for euthanasia had been both properly informed and competently made. Finally, the privacy of the doctor/patient relationship would, it has been argued, make it almost impossible to ensure that the patient had not been pressurised into requesting euthanasia.[123]

The obvious response to these arguments is that we already allow patients to make decisions which will result in their deaths through refusals of life-prolonging treatment. A patient who is connected to a ventilator may be depressed, and we may wrongly judge her to be competent, but this inescapable risk of error does not persuade us that we should prevent patients from taking life and death decisions. Instead the appropriate response is a careful assessment of her decision-making capacity. Nor do we think that the principle of patient confidentiality represents an insurmountable obstacle to our ability to protect vulnerable patients from being coerced into agreeing to the withdrawal of life-prolonging treatment.

(ii) *Preventing abuse:*

It has been suggested that if euthanasia were legal, elderly patients would be pressurised into electing a premature death by unscrupulous relatives. Pressure may also come from the medical profession, since euthanasia would be cheaper than providing optimum palliative care, and might appear to be a cost-effective "treatment" for old age and terminal illness.[124] It is also common for elderly people to perceive themselves to be a burden to their families, and there is a danger that they might request euthanasia despite their desire to go on living.

The legalisation of euthanasia would not present a unique opportunity for the mistreatment of the elderly. Common practices, such as withholding or withdrawing life-prolonging treatment *without* the patient's consent, may pose an even greater risk to vulnerable individuals. Do Not Resuscitate orders, for example, are often made without consulting the person whose life is at stake. Life-prolonging treatments are commonly withheld from competent patients because the doctor judges treatment to be futile, even if the patient herself would prefer to live on. And if we are concerned to protect vulnerable patients from electing a premature death against their wishes, we should probably be *more* concerned about refusals of life-prolonging treatment, where the patient's decision must be respected even if it is wholly irrational.

[121] [2002] 1 FLR 1090.

[122] J D Velleman "A Right of Self-Termination?" (1999) 109 Ethics 606–628, 618.

[123] D Callahan and M White "The Legalisation of Physician-Assisted Suicide: Creating a Regulatory Potemkin Village" (1996) 30 *University of Richmond Law Review* 1.

[124] L Gormally n 3 above.

A carefully regulated system would offer much more effective protection than a blanket ban which simply pushes the practice underground and magnifies the risk of abuse. An analogy could be drawn with arguments made prior to the partial decriminalisation of abortion: advocates of legalisation argued that abortion's continued illegality ensured that pregnancies were terminated in unsanitary conditions, without the safeguards and control that would be possible if doctors were allowed to provide women with safe, legal abortions.[125]

(iii) *A slippery slope?*

The slippery slope claim is that even if we accept that euthanasia might sometimes be reasonable, we should nevertheless prohibit it because sanctioning some compassionate acts of killing would make it difficult to prevent doctors with less benevolent motives from ending their patients' lives.[126] The argument suggests that although we might be able to distinguish paradigm cases at the top of the moral slope from those at the bottom, it would be very difficult to locate or police the line between acceptable and unacceptable practices towards the middle of the slope. Yet this "grey area" problem exists whenever we attempt to regulate *anything*.

Would legalising euthanasia make involuntary killing more likely? We might answer this question by examining statistics from countries which have legalised euthanasia, but there are different and contradictory interpretations of the available data. Despite their essentially empirical character, slippery slope arguments are seldom decisively proved or refuted by the available evidence, because the evidence will inevitably be interpreted through the partisan lens of the opponent or the supporter of legalisation.

A blanket ban seems a peculiarly blunt approach to regulation, especially since the consequence for patients who do clearly merit access to euthanasia will be a painful or otherwise intolerable death. It would be more logical to advocate regulations which confine access to euthanasia to patients whose circumstances lie at the top of the moral slope (whatever those might be), and prohibit it in all other cases. Hypothetical speculation about an as yet unwritten law's possible future inefficacy does not offer adequate justification for a refusal to contemplate even thinking about regulation.

(c) *Protecting the Medical Profession*

The British Medical Association has consistently opposed the legalisation of euthanasia on the grounds that for the medical profession to "acquire an additional role alien to the traditional one of healer" would be "in tension with the fundamental role of doctors".[127] If doctors had to learn how to kill, the medical profession's image of itself as a healing profession would be fatally undermined.[128]

It might be argued that it is intrinsically good for doctors to cultivate adherence to a rigorous ethical code which absolutely forbids killing, or that the complete prohibition of medicalised killing promotes optimum patient care by fostering a relationship of trust and confidence. Patients are able to trust their doctors, it is argued, precisely because they belong to an honourable profession with its own strict ethical codes. But of course, we already know that doctors routinely make decisions which shorten their patients' lives, although none of the lawful ways in which doctors routinely cause their patients' deaths have the brutal linguistic resonance of "direct killing": withdrawing treatment "lets nature take its course"; a life-threatening dose of analgesics is simply intended to relieve pain. I would argue that euthanasia's continued illegality is principally directed towards preserving this symbolic moral ideal about the proper limits of medical power.

2. Contrasting Unlawful and Lawful Ways to Shorten Patients' Lives

From the patient's perspective, the line the law draws between lawful and unlawful life-shortening practices makes very little sense. If we allow doctors to engage in some practices which will end their patients' lives, why not permit doctors to accomplish exactly the same end more swiftly and painlessly?

Lawful and unlawful life-shortening practices can be distinguished only by adopting the medical practitioner's perspective. For example, the practice of terminal sedation, whereby a patient is lawfully sedated into a coma, and then removed from the artificial ventilator which is keeping her alive, is functionally indistinguishable, from the patient's point of view, from active euthanasia.[129] For the dying patient, it is difficult to see why terminal sedation should be treated so differently from euthanasia.

[125] *See* further S Sheldon "The Abortion Act 1967: A Critical Perspective" in E Lee (ed) *Abortion Law and Politics Today* (London, Macmillan, 1998) 43–58.

[126] D W Brock "Voluntary Active Euthanasia" (1992) 22 *Hastings Center Report* 10–22.

[127] *End of Life Decisions Views of the BMA* (London, BMA, 2000).

[128] L Kass and N Lund, n 36 above.

[129] *See* further D. Orentlicher n 7 above, 855–7 and M P Battin n. 43 above, 104–5.

In *Re B (adult: refusal of medical treatment)*,[130] the clinicians involved in Ms B's care did not want to withdraw artificial ventilation, but were prepared to adopt a "one-way weaning" programme, gradually reducing the breaths supplied by the ventilator, even though death would take several weeks. From the doctors' perspective, one-way weaning was preferable to complete withdrawal because it would be more like "letting die", and less like killing. It would be easier for them to live with. But however difficult it might be for the doctors, from the patient's perspective, a protracted and perhaps painful death is self-evidently and emphatically worse than a quick, painless one.

In the same year the English courts heard Mrs Pretty's request for assistance in dying. Mrs Pretty was not connected to artificial life-support, and hence needed more active assistance in order to end her life. But while Ms B could insist upon compliance with her wish that her life be brought to a quick and painless end, Mrs Pretty had to endure a distressing and frightening death.[131] From the patient's perspective, it makes little sense that access to a "good" death should depend upon something as apparently arbitrary as whether or not one is able to breathe unaided. It also seems strange that doctors can end the lives of patients (like Tony Bland) who have many years of pain-free existence ahead of them, while no assistance can be provided to competent adult patients (such as Dianne Pretty) whose final few days have become unbearable.[132]

Most of us would prefer to die quickly and at home, in the presence of someone we love, yet none of the lawful means of ending patient's lives promote this sort of death. Withdrawal of life-sustaining treatment invariably takes place in hospital, and when artificial nutrition and hydration is withdrawn, the patient will slowly starve to death. The moment of death is unpredictable, and the patient's family may not be present. Voluntary euthanasia, on the other hand, could be given to a patient in her home in the presence of friends or relatives. Evidence from the Netherlands indicates that the relatives of patients who die as a result of euthanasia cope better with bereavement than the relatives of patients who die naturally, because they have the opportunity to talk openly about dying and say goodbye, and are prepared for the time and manner of the death.[133]

3. Conclusion

Competent adult patients seeking to end their lives will generally fall into one of three groups. First, there are those who are able-bodied enough to take their own lives. Suicide is not a criminal offence;[134] therefore it is lawful and relatively straightforward for patients in this group to end their suffering by taking their own lives. Secondly, there are patients, such as Ms B, who are connected to artificial means of life support and have the right to insist that their doctors do something to bring their lives to a quick and painless end. Finally, there are patients like Dianne Pretty, who fall somewhere in between. They are not sufficiently able-bodied to commit suicide, but neither are they sufficiently disabled to require artificial life support. This third group of patients have no option but to endure an unendurable death.

The purpose of this paper has been to show that we can only defend an absolute prohibition on euthanasia if we ignore the needs of this small sub-set of patients for whom it may represent the only way to relieve their pain or distress. This disregard of the individual patient's perspective is wholly at odds with the trend towards a patient-centred approach to medical law and ethics.

What is particularly important about the prohibition of euthanasia is that it admits absolutely no exceptions. However compelling an individual patient's reasons for wanting her doctor to help her to die, and however sympathetic a doctor might be to her request, euthanasia remains illegal. No other rules of ethical conduct have this absolute quality—it is always possible to make an exception if there are sufficiently compelling reasons. Instead of anticipating the different situations in which euthanasia might be requested, and attempting to work out which requests should be honoured, and which refused, the law insists that all requests, including those from people who are plainly both competent and suffering truly intolerable distress, must be turned down. A refusal to accept that there might be circumstances which would justify making an exception from a general rule against active euthanasia does not take seriously enough the perspective of a competent patient for whom life has become unbearable.

[130] [2002] 1 FLR 1090.

[131] Mrs Pretty died precisely the death she feared 12 days after the ECHR rejected her application.

[132] M Freeman, n 20 above, 606.

[133] N B Swarte *et al*, "Effects of euthanasia on the bereaved family and friends: a cross sectional study" (2003) 327 *British Medical Journal* 189.

[134] Suicide Act 1961, s 1.

Memorandum by Dr Bert Keizer

EUTHANASIA IN THE NETHERLANDS

Euthanasia is the handing or administering of an overdose to a patient at his or her request. It is allowed under the following conditions:

- The patient suffers unbearably without any prospect of recovery.
- The request for death is not uttered in the course of a psychiatric disease such as dementia or depression.
- The request is durable and consistent ie not uttered in a flash of despair.
- The request is put in writing.
- The doctor calls in a colleague who is not in any way involved in the case and this second doctor evaluates the above and puts her or his findings in writing.
- Death is brought about in a humane manner using the type of medication particulalrly suited to such a course of action.
- After the patients death the doctor reports to the authorities in the figure of the coroner who is called in to assess the procedure.

These conditions sound pretty straightforward, and yet, it has taken us some 30 years of intense social debate before we were agreed about them. Many people are pro euthanasia when asked in passing, but when it comes to working out a proper procedure which can be made to work in practice, it turns out to be a very complicated matter.

The patient's suffering being *unbearable* involves a hopelessly subjective judgment. This is not the case when it comes to the prospect of recovery. Doctors know the expected course of a serious disease and can give an objective estimate of the prognosis.

As to *durablilty:* when a patient asks for death on Tuesday and would be handed the overdose on Wednesday the doctor involved would be in deep trouble. A question of this complexity, an answer with such a grave consequence, these are not matters that can be decided overnight.

Depression is often used in the manner of a Catch-22: anyone asking for death must be suffering from a depression and this depression must be treated, not the patient killed. This is wrong for two reasons: many patients asking for death are not depressed, and, secondly: the hidden suggestion that depressions can be treated easily is of a horrible flippancy.

It sounds strange but it takes some skill to let a patient die *humanely.* Therefore the use of certain drugs is strongly advised instead of outlandish often jolting and sometimes agonzing ways of ending a patients life.

It is useless to worry about the slippery slope. Once a society has decided that euthanasia is allowed in certain cases, one is on it. Thus in Holland we have given up the condition that a patient must be in a terminal situation. Next, mental suffering was allowed to be unbearable and in some cases to be without any prospect of revovery. Then one's future *dementia* was suggested as a reason for a request for death. And lastly the suffering of extreme old age with all it entails in terms of social isolation, loss of children and bodily decay was put up as sufficient reason in itself to ask for death. Unsuccesfully, as it turned out, because the Dutch judiciary decided in the latter case that euthanasia was not allowed and condemned a GP accordingly. Only a provisional sentence was pronounced and the doctor was praised by the court for his frankness about his doings. In that praise the awkwardness of the entire situation was neatly expressed.

Was legalisation a success in Holland?

Yes, if one considers the unsavoury kinds of messing around doctors inevitably fall into when not being overlooked by colleagues or society at large. Under the rule of law, patient and doctor both feel safer, the one in asking, the other in supplying euthanasia.

No, legalisation failed if one realises that inspite of all the work done in Dutch society still only 54 per cent of cases are being duly reported. There is some slight consolation in the fact that the number of duly reported cases in Britain is 0 per cent, a figure assuredly not reflective of reality, because we know that the practice of euthanasia is a given, ever since the days of the Hippocratic oath. We had better realise that the practice was abjured in that spurious oath precisely because it occurred.

The problem of euthanasia has not been solved in the Netherlands. But if we have achieved anything it is the growing realisation, also internationally, that there is such a problem.

Finally, I believe, on the grounds of the more than 1,000 deathbeds I attended as a physician, that euthanasia is a blessing in certain exceptional situations, yet I would rather die in a country where euthanasia is forbidden but where doctors do know how to look after a dying patient in a humane manner, than I would in a country where palliative medicine is ignored but euthanasia can be easily arranged.

About the author.

A A Keizer BA MD born 1947 in Amersfoort Holland.

Lived in England from 1968–1972. Studied philosophy in Nottingham University. Then medicine at the Univerity of Amsterdam. Qualified as a doctor in 1981, worked shortly in Kenya Africa, and has been working as a geriatrician in Amsterdam for 23 years.

Published a collection of personal sketches and philosophical essays about his work as a doctor in a nursing home in 1994 in the Netherlands. The book was translated into German, Spanish, Japanese, Danish, Swedish and French.

The author translated his work into English under the title of *Dancing with Mister D* published in 1996 by Transworld—Doubleday in London.

2 August 2004

Memorandum by Dr Helga Kuhse

As a researcher in the field of medically assisted dying, I am writing in support of the *Assisted Dying for the Terminally Ill Bill* [HL].

Before doing so, allow me to introduce myself. I am the former Director of the Centre for Human Bioethics and Associate Professor at Monash University. I am now semi-retired and currently hold the position of Senior Honorary Research Fellow at the University. Throughout my professional career, spanning nearly 30 years, I have researched various fields within bioethics. Ethical issues, as they arise at the end of life, have been one of my special interest areas. I have published more than 150 professional articles and 12 books in the field of bioethics, including many publications on medical end-of-life decisions.

I am co-founder of the International Association of Bioethics and have served as a Consultant on medical end-of-life decisions and euthanasia

- to the Human Rights Commission of Australia;
- to the Government of the Australian State of Victoria;
- to the Select Committee on Euthanasia to the Legislative Assembly of the Northern Territory of Australia;
- as an Expert Witness for the Northern Territory of Australia [on its voluntary euthanasia law] before the Supreme Court;
- as a Witness appearing before the Social Development Committee of the Parliament of South Australia.

My research into medical end-of-life decisions and other ethical issues has been supported by competitive grants from the Australian Research Grants Foundation, The Australian Research Council, The National Health and Medical Research Council and Monash University.

In the course of my thinking and research in the area, I have reached the conclusion that there are two broad grounds for legalizing direct help in dying to terminally ill patients who request such help.

(1) The first reason is an ethical reason, in the narrow sense of the term. With many others, I take the view that it is wrong to deny a terminally ill and suffering patient direct help in dying. To deny this right to competent, well-informed patients is to fail to treat them as persons and as autonomous moral agents. It shows lack of moral respect for persons as persons.

(2) The second cluster of reasons encompasses ethical grounds in the wider sense of the term. It relates to issues of public policy, to questions of justice and fairness, and to control and regulation.

My attached submission will focus on Point 2. My reason for focusing on the second, rather than the first, point is this:

In multicultural and pluralist societies, such as Britain or Australia, people give very different answers to questions such as whether voluntary euthanasia, stem-cell research, or organ donation (to give just three examples) are morally right or wrong. Because these different answers have their source in different value systems, they cannot be shown to be true or false, in the ordinary sense of those terms.

This raises the question of an appropriate *social* response. Given that there is fundamental disagreement about the morality of a practice, how should modern pluralistic and liberal societies respond to it: Should they allow or prohibit the practice, and on what grounds?

It is now widely accepted that personal autonomy or liberty is a very important value and that it is inappropriate for the state to either adopt a paternalistic stance towards its mature citizens, or to restrict their freedom through the enforcement of a particular moral point of view. Only if one person's actions cause harm to others is it legitimate for the state to step in, and to bring in laws that restrict individual liberty. As John Stuart Mill put it in his famous essay *On Liberty:* "The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others . . . Over himself, over his own body and mind, the individual is sovereign."

If this standpoint is accepted, it follows that the House of Lords, in its deliberation on the *Assisted Dying for the Terminally Ill Bill,* should not so much concern itself with the question of whether or not it is intrinsically morally right or wrong to ever render direct help in dying, but with rather the issue of Public Policy: whether there are good grounds for retaining the prohibition on direct help in dying for terminally ill patients who request such help.

Introduction

In this submission I shall focus on two clusters of problems that may be grouped under the following two headings:

1. The Problem with Drawing Boundaries

Existing law prohibits the intentional termination of life. This assumes that a morally relevant and/or practically workable distinction can be drawn, in end-of-life patient-care, between cases of the intentional termination of life, on the one hand, and other end-of-life decisions—such as non-treatment and palliative care decisions—that are tolerated by the law.

This submission will show that the assumed distinction between lawful and unlawful medical end-of-life decisions is marred by serious conceptual and practical problems.

2. The Problem with Prohibition

It is often assumed that a restrictive public policy approach that prohibits direct or intentional help in dying to the terminally ill who request it ("assisted dying", as defined in the Assisted Dying for the Terminally Ill Bill), is more protective of patients as a whole than a liberal approach. As an earlier House of Lords Select Committee put it: "The prohibition (of intentional killing) is the cornerstone of law and of social relationships. It protects each of us impartially, embodying the belief that all are equal. We do not wish that protection to be diminished."[135]

This submission will show that empirical evidence challenges this belief. Patients as a whole appear to be better protected by laws that regulate assisted dying than by laws prohibiting it.

Terminology: My discussion is limited to competent, terminally ill patients, as defined in the *Bill*; and I shall use the term "assisted dying" to refer to both medically assisted suicide and voluntary euthanasia for the terminally ill.[136]

1. The Problem with Drawing Boundaries

Around 40 per cent and more than 80 per cent of deaths are preceded by a medical end-of-life decision, that is, an action or an omission undertaken by the doctor in the knowledge or belief that the patient will die earlier as a consequence of that decision than she or he would if that decision were not taken. In other words, with or without the patient's consent, doctors are taken courses of actions that will often determine when and how a patient dies.

Doctors who engage in these end-of-life decisions are not necessarily acting contrary to the law. Rather, in many countries it is lawful for doctors to implement decisions that will shorten the patient's life. Under certain circumstances, doctors can lawfully withhold or withdraw life-sustaining treatment, and a consensus is

[135] House of Lords, *Report of the Select Committee on Medical Ethics*, Vol 1, Report, London: HMSO, 1994, p 48.

[136] While some writers hold that the two practices are morally distinct as far as the role of the doctor is concerned, I do not share that view. A doctor who prescribes a lethal drug, at the patient's request, is as morally responsible for the foreseen outcome—the patient's death—as a doctor who, at the patient's request, administers a lethal drug. I also believe it would be bad public policy to limit legislation to medically assisted suicide. Not all patients are capable of ending their own lives, and attempts at suicide may fail.

evolving according to which doctors may administer life-shortening pain of symptom control, in full knowledge of their "double effect".

There are a number of reasons why the present situation of permitting some but seemingly prohibiting other medical end-of-life decisions is problematic:

Discrimination

Non-treatment decisions:

Contrary to what the House of Lords Select Committee on Medical Ethics stated in its Report[137], the continued prohibition of assisted dying in the practice of medicine does not "protect [. . .] each of us impartially". Rather than treat all patients impartially, and give expression to "the belief that all are equal", laws that prohibit assisted dying are, on the face of it, discriminatory: they allow some patients—those who are fortunate enough to require life-support—to take control of their dying process, and to shorten their suffering; they do, however, deny the same rights or opportunities to others: those who are in the unfortunate position of not requiring life-support, but whose suffering is just as great, and may be greater, than that experienced by patients in the first group.

Palliation

Modern palliative care can help many patients, but can unfortunately not help all patients. At the end of life, some 15–20 per cent of patients referred for palliative care may experience intolerable pain, delirium, shortness of breath, nausea, persistent vomiting that is refractory to the usual therapies.[138] Some patients can be helped only by what has been termed "terminal sedation", but terminal sedation, it has been argued, is a form of assisted dying indistinguishable in all its relevant features from currently prohibited forms of the intentional termination of life[139], with some doctors referring to it as "slow euthanasia"[140].

This leaves one with the following conclusion:

(a) If terminal sedation is rejected as a morally licit and lawful means of aiding a patient's death, then patients suffering refractory pain cannot be helped by available medical care; and some of these patients may also feel discriminated against on the grounds that in addition to not being able to refuse treatment, they are also experiencing intolerable and unrelievable pain and suffering.

(b) If terminal sedation is accepted as lawful, then doctors will be permitted to intentionally end the lives of patients "slowly" and in a—for many patients, relatives, and health care professionals—distressing way, but not quickly and in according with the patient's own considered wishes, values and beliefs. As one well-known physician has put it:

> In many cases, terminal sedation amounts to euthanasia because the sedated patient often dies from the combination of two intentional acts by the physician—the induction of stupor or unconsciousness and the withholding of food and water . . . It is the physician-created state of diminished unconsciousness that renders the patient unable to eat, not the patient's underlying disease.[141]

The Problem with "Intention"

How can one be sure what doctors intend to bring about when they engage in end-of-life decisions? Under the Principle of Double Effect, an outwardly identical action or omission, such as administering a potentially life-shortening dose of a palliative agent, or the withdrawing of life-support, can be a case of impermissible assisted dying or the intentional termination of life, depending on what the agent intends to bring about. Since intentions are internal mental states, often only the doctor herself will know what she intended to do when she did what she did.

The legal presumption is that doctors administering palliative care to dying patients, and those who withhold or withdraw life support from the terminally ill, are not intentionally terminating these patients' lives. But what do doctors actually intend when they engage in end-of-life decisions?

[137] *See* note 1.

[138] *See* eg, N I Cherny, R K Portenoy, "Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment", *Journal of Palliative Care:*, Vol 10, (2), 1994, pp 31–38; David Orentlicher: "The Supreme Court and Physician-Assisted Suicide—Rejecting Assisted Suicide but Embracing Euthanasia", *New England Journal of Medicine*, Vol 337 (17), 23 October 1997.

[139] *See* eg, Helga Kuhse: "Why Terminal Sedation is no Solution to the Voluntary Euthanasia Debate", in T Tannsjo: *Terminal Sedation: Euthanasia in Disguise?*, Kluwer, 2004.

[140] *See* eg, J A Billings, D Block: "Slow euthanasia", *Journal of Palliative Carer*, Vol 12(4), 1996, pp 21–30.

[141] David Orentlicher, see footnote 4.

A number of important, comparable nationwide studies—conducted in the Netherlands, Australia and Belgium—asked doctors about their intentions; they can shed some light on this question. Here my main focus will be on some data from the Australian study. The Committee may want to access the original studies.[142]

Non-treatment decisions:

The study found that of all Australian deaths in the period, 28.6 per cent were preceded by a non-treatment decision that in the doctors' opinion would hasten the patients' death.

In 24.7 per cent of all deaths, the doctors acted with the intention of shortening the patient's life; in 3.9 per cent of all deaths was there no intention to shorten the life of the patient.

Palliation

30.9 per cent of all Australian deaths were preceded by a palliative care decision. 24.4 per cent did not involve an intention to hasten death; 6.5 per cent involved a partial intention to hasten death.

The Administration of Prescription of drugs, Administered or prescribed with the explicit intention of hastening the end-of-the patient's life:

The study found that 5.3 per cent of all Australian death involved this form of medically assisted dying.

Setting partially intended deaths to one side, this means that approximately every third patient's death was preceded by a decision that was directly intended to result in their death.

This shows that existing laws prohibiting the intentional termination of life are not being observed by Australian doctors. While the prohibition of the intentional termination of life may prevent some doctors from using fast-acting non-therapeutic drugs, prohibition does not, and cannot, prevent doctors from intentionally ending the lives of suffering patients in some other "lawful" ways.

This brings us to the cluster of problem associated with prohibition.

2. The Problem with Prohibition

Prohibition does not work

The reason for the non-workability of the prohibition of the intentional termination of life lies in the mainstream legal assumption that doctors do not intend all the foreseen "natural" consequences of their actions and omissions. Rather, existing laws rely, at least in part, on a subjective notion of intention. If the notion of intention where understood in a wide objective sense, then the death resulting from each and every deliberate medical-end-of-life decision, to the extent that it was not accidental or inadvertent/would be taken to be the intended consequence. Since this is not the mainstream view, it entails that current regulatory frameworks and laws are at least to some extent based on a subjective notion of intention.

This makes for the extreme malleability and "constructability" of medical end-of-life decisions and with this, for the unworkability of existing laws.[143] Existing laws can neither prevent doctors from intending what it is impermissible to intend—the death of a suffering and dying patient, for example—nor effectively prevent them from implementing those intentions. A doctor who does not, for whatever reason, wish to administer a non-therapeutic lethal drug to aid the patient's passing, will often be able to achieve the same result by using a therapeutic drug, by a non-treatment decision, or both.

Lack of transparency and consent

The legal focus on the doctor's intention in medical end-of-life decisions offers neither transparency nor regulatory protection. Rather than encourage honesty and openness in the doctor/patient relationship, it encourages, self-deception and hypocrisy, and seems to lead doctors to act without their patients' consent.

[142] Helga Kuhse, Peter Singer, Peter Baume, Malcolm Clarke and Maurice Rickard: "End-of-life decisions in Australian medical practice, *Medical Journal of Australia*, Vol 166, 17 February 1977; P J van der Mass, G van der Wal, I Havercate et al: "Euthanasia, Physician-Assisted Suicide an d Other Medical Practices Involving End of Life in the Netherlands, 1990–95", *New England Journal of Medicine*, Vol 335, 1966, pp 1699–05. Luc Deliens, Freddy Mortier, Johan Bilsen, et al: "End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey", *The Lancet*, Vol 356, 25 November 2000, pp 1806–11.

[143] John Griffith: "The Regulation of Euthanasia and Related Medical Procedures that Shorten Life in the Netherlands", *Medical Law International*", Vol 1, 1994, pp 137–158.

The Slippery Slope—Which way does it slope?

It has often been claimed that the acceptance of assisted dying [voluntary euthanasia], at the patients' request, will lead to non-voluntary or involuntary euthanasia. The British academic J Keown, for example, has argued that this is illustrated by evidence emerging from the Netherlands, where doctors have been able to practice voluntary euthanasia for a number of years: ". . . since [voluntary] euthanasia became widely tolerated in the Netherlands, thousands of patients have had their lives intentionally shortened without an explicit request."[144]

The claim by Keown and others that voluntary euthanasia leads to non-voluntary euthanasia is not born out by empirical studies. Rather, comparable international empirical studies suggest that the acceptance assisted dying at the patient's request, is associated with fewer—not more—cases of non-voluntary euthanasia.

The Australian survey into medical end-of-life decisions was modelled on the 1996 Dutch study.[145] One of the central findings of the Australian study was that 3.5 per cent of all Australian deaths result from the administration of drugs explicitly intended to end patients' lives without their consent. The figure was five times higher than in the Netherlands, where it was 0.8 per cent and 0.7 per cent, respectively. [The asymmetry between the Dutch and Australian figures is also born out by a comparable Belgium study Belgium doctors administered drugs with the explicit intention of ending the patient's life in 3.2 per cent of all deaths.[146]

These findings [for further important data, please consult directly the Dutch, Australian and Belgium studies] raise the question of why more Australian [and Belgium] than Dutch doctors chose intentionally to end the lives of some of their patients without the patient's consent. One plausible explanation is that since existing laws prohibit the intentional termination of life, doctors are reluctant to discuss medical end-of-life decisions with their patients lest these be construed as collaboration in the intentional termination of life.

Conclusion

To conclude: there appears to be good evidence to suggest that laws prohibiting the intentional termination of life, but permitting the withholding and withdrawing of treatment and the administration of life-shortening palliative care, do not prevent doctors from intentionally ending the lives of some of their patients.

There are also good grounds for believing that these laws are discriminatory and unjust, that they encourage hypocrisy and lack transparency, and the unconsented—to termination of patients' lives.

For the purposes of public policies and laws governing medical end-of-life decisions for competent patients, we should stop asking whether a doctor "intends" death or merely "foresees" it, whether death comes about as the result of an action or an omission, or as the result of administering a slow-acting therapeutic or a quick acting non-therapeutic drug.

What is needed is a single regulatory framework for all medical end-of-life decisions for competent patients, a framework that does not rely on the largely unworkable notion of intention, but on the substantive notion of respect for the patient's autonomy, which finds expression in the procedural requirement of consent. Under such a framework, patients and doctors would be free to jointly decide on a mode of dying that best meets the needs of patients. For many patients this would involve foregoing life-sustaining treatment, and accepting palliative care. But for some patients this would also involve direct help in dying, through the prescription or administration of a drug.

2 August 2004

Memorandum by H M Laane, MD, GP, PhD, MAS

Summary and Conclusions—Based on My Experiences as a Dutch GP

1. When (optimal) palliative care is exhausted, Euthanasia/Doctors Assisted Suicide (EU/AS) is a medical option for patients:

— With severe and non curable diseases,

— Who are going to die anyway,

— Who are suffering physically and/or mentally,

— After informed decision.

[144] As quoted in the Australian Senate and Constitutional Legislation Committee report: *Consideration of Legislation Referred to the Committee—Euthanasia Laws Bill 1996*, Canberra: The Parliament of the Commonwealth of Australia, March 1997, p 103.

[145] See footnote 142.

[146] See footnote 142.

2. The autonomy of the patient that chooses assisted dying (EU/AS or terminal sedation) must be respected as long as the criteria (above) are fulfilled.

3. Cases where patients come to doctors seeking assisted dying because they are "tired of life" do not constitute a medical issue. These patients do not make the above criteria.

4. A promise from the doctor not to let their patient suffer enables the patient to deal with their death. This promise of help, should it be needed, enables the patient to continue with his/her life while they are waiting for their death.

5. The patient is in fact the only person who can tell his limits. They will be different for different people and can involve a combination of the following:

- Not being able to do things he/she did before
- The loss of their skills: not able to cook or dial a phone number
- The loss of senses: blind, deaf
- The loss of the taste
- The loss of communication, also due to mental dysfunction
- Incontinent for urine and faeces or severe constipation with colic pains
- Persistent nausea/persistent vomiting
- Dyspnoea
- Severe itching
- Mental pain
- Etc.

6. It is easy for us to understand physical pain. However, it much more difficult to understand another's mental pain/suffering.

7. Who has the right to choose? If nature takes its course, animals and men die in a natural way. However, due to our medical knowledge and technology, we are able to keep people alive beyond the borders of natural death—by: days, weeks, and even years. It is now the case that patients hardly get the opportunity to die.

8. The practice of EU/AS in the Netherlands cannot be exported to other countries *per se*. It is possible in the Dutch system because it provides the patients with the latest treatment developments. In the Netherlands all costs for all ill patients are completely reimbursed by the insurance system, so no financial aspects are involved.

9. The task to end a patient's life is a disturbing personal experience. It is emotionally very difficult. The doctor has to live with his own emotions. It is and never will be, a routine medical practice. You take it home with you. It is a scar on your soul.

10. At the other hand I, as a doctor, can offer my patients a death with human dignity, in which he/she is able to talk with his family and friends and can see goodbye to life, voluntary and without suffering.

11. Then I know, I feel and I can say as a doctor: "I have done a good job".

Some Detail About my Personal Experiences 1973–2004

1. My first personal experience of assisted dying was in 1973 when an old sailor asked me for help to die. He was dismissed from the hospital because there wasn't any treatment for his (lung) cancer and the metastases in bones and liver. He was suffering a lot of pain, was extremely dyspnoeic and had a severe itching. The specialist couldn't offer any relief at all. At that time I was horrified by the idea that somebody asked me to "murder" him, but on the other hand I realised that I wasn't able to help him in a way that I could relieve the symptoms sufficiently. I didn't know what to do, so I referred him to a nursing home. He died eight days later and his wife told me that he had a horrible time. At that moment I felt that I had betrayed my patient because I hadn't found the right solution.

2. In that same year—1973—there was a lawsuit of a Dutch (female) GP. She had helped her mother to die when she was in a medical horrible situation. I was very interested and followed this case. In fact in this case there were the same principles involved that I had encountered with my patient: "the protection of life" and "the obligation from the doctor to help a patient not to suffer".

3. Between 1973 and 1976 I was able to relieve the symptoms of the terminally ill and dying patients. But in 1976 I was confronted again by a desperate medical "case". For this patient my medical/professional knowledge and skills weren't enough to relieve his symptoms although he also had the consultations of two specialists. This patient asked me to help him to die. After a difficult decicision-making process I promised him

to help. But now I had another problem: how do you let your patient die in a gentle way? I asked advice of a friend (anaesthesiologist) and he helped me out with the right medications. He explained the procedure: first of all induce a coma and in the second phase administer curare-medication, so the heart will stop beating. So I did. His daughter was present and after the death of her father she was very relieved and thanked me on behalf of her father. This was a very emotional moment.

4. From the beginning of the eighties I helped other patients to die, not frequently but with an average of 1 patient per two to three years. All but one were cancer patients. All were treated properly (operations, chemotherapy and radiation). And because of these treatments those patients "lived beyond the border of natural death", sometimes many years. But also because of these treatments their final medical situation turned into "nightmares" in which palliative care wasn't helping any more.

5. In the vast majority of the cases as a GP, you can offer efficient palliative care to your terminally ill patients. But this is not always the case. Sometimes there were exceptions and I helped those "palliative resistant" patients to die. I was able "to correct" the unwished extremely negative effects of their medical treatments.

6. Also from the beginning of the eighties I reported to the responsible authorities that I wasn't able to issue a certificate of natural death. You have to realise that at that time, when you reported a case of euthanasia, the Police officers (in uniform) came to the house of the deceased. They then told you that you were a "suspect of an offence". I had to go several times to Police stations to be interrogated. In all cases I was "cleared as a suspect". However, such procedures each took at least three years, so for a doctor, it was an exhausting procedure. And now in the year 2004, I, this "suspect" from the seventies and eighties, am now consulted by the Dutch Court as an expert. Over the past 20 or so years, times have certainly changed in the Netherlands.

7. Based on my personal experiences in assisted dying, in the second half of the eighties I wrote a number of articles to inform other GPs.

8. In the beginning of the nineties the number of terminally ill AIDS patients had started to grow very rapidly. Because I was also involved in AIDS research many people with aids (PWAs) consulted me. At that time there wasn't a cure, so I saw all complications in terminally ill PWAs: no cure and no hope. Because many PWAs realise that they were going to die and because they had seen "needless" suffering with friends, a great number of them asked for euthanasia if their suffering couldn't be resolved. In 1992 in Amsterdam about 30 per cent of the terminally PWAs died by EU/AS. I published five articles on this subject in the period 1992–96. One of those articles is added to this submission.

9. In 1996–97 the new combination therapy for aids was introduced. This therapy had very good results. This was also reflected in the number of PWAs who died by euthanasia/assisted suicide (EU/AS)! In1992 45 PWAs died by euthanasia in Amsterdam, and a lot more for the Netherlands! However, in 1999 (three years after the start of the combination therapy) there were only six cases of EU/AS in the whole of the Netherlands.

This shows that when the prospects for medical treatments improve, the need for EU/AS decreases.

10. When I started in the seventies the level of palliative care was in accordance to the level of medications and treatments of those days. The last 30 years there has been a huge development in the possibilities of palliative care and nowadays we can offer our patients a lot more.

This also illustrates that the fear of a "slippery slope in the Netherlands" hasn't come true: at the moment we can offer our patients enough prospects and alternatives, and as a result, the need for EU/AS is going down.

11. Being in most cases also the family doctor of the relatives, I have experienced that they are so relieved about the possibility of "dying with dignity". I have never met with negative reactions from relatives.

My Experiences as a Second Opinion Doctor

1. From 1995 I was involved in the so-called SCEN-project (second consultation for euthanasia in the Netherlands). We started this project in Amsterdam. Because of the high quality of the second consultations that SCEN provides, this project has been implemented in the whole of the Netherlands.

2. The expertise of the SCEN-doctors is not limited to only EU/AS. As a second opinion doctor I have done over 150 second opinions, >100 as a SCEN second opinion doctor. Through reviewing all those second-opinions, my first conclusion is that in the vast majority of those cases the criteria of carefulness had been fulfilled by the patient's doctor. In 21 cases this was not so. In 13 cases I visited the patients again three months to a year and a half later. After this second visit the criteria were fulfilled. In eight cases it became clear that EU/AS was not the right option. In several cases the patient was (already) in coma, in several cases the patients weren't able to express their will explicitly and in several cases the symptoms should relieved by medical treatment and two patients died naturally during the period of the second opinion.

3. Because EU/AS is only an option when palliative care is exhausted all SCEN-doctors have followed additional palliative training and give advice for proper palliative treatment.

4. Second opinion doctors must be very experienced and skilled doctors. In the Netherlands all second opinion doctors have a history of at least five years of practice as a family doctor or nursing home doctor and must have personal experience with EU/AS. If those criteria are fulfilled they have to follow the specialised SCEN-course to be a qualified second opinion doctor.

My Experiences with Monitoring Commission

1. Since the monitoring commissions for assisted dying have been installed, I have sent my reports as an attending physician and as a consulting physician. This procedure is relatively simple and as an attending physician, you will get an answer within a couple of weeks and the final results in most cases within three months. It is a satisfying procedure compared with my experiences in the eighties!

APPENDIX 1

Curriculum Vitae of Henk-Maarten Laane, MD, GP, PhD, MAS

1967–1990: Teacher in Gross Anatomy and Embryology University of Amsterdam

1973–1984: Coroner for the City of Amsterdam

1973–2004: General Practitioner in Amsterdam

1982–2000: Teacher in General Practice—University of Amsterdam

1995–2004: Second opinion doctor in the SCEN project

1996–2004: Teacher for the (second opinion) doctors in the SCEN organisation

2004: Consultant for the Dutch Court on Euthanasia issues

1987–1989: Six articles about EU and AS in Dutch Magazines for GP's

1992–1996: Five articles on the subject "Euthanasia and Assisted Suicide in Aids patients"

1980–2004: presentations, interviews for newspapers, magazines, radio and TV

APPENDIX 2

Example of a Report of Doctors Assisted Suicide

Dr H M Laane, GP

Healthcentre Nellestein

Liendenhof 114

1108 HE Amsterdam

phone: 020-6962020

Amsterdam, 28 February 1995

Report of Doctors Assisted Suicide

Concerning Mr X Xxxxxxx, 4 April 1966

Address: .....

Amsterdam

I am the attending physician of the above-mentioned patient.

I know him several years with HIV infection.

After the diagnosis of "oral hairy leucoplacia" in combination with thrombocytopenia, he was diagnosed as an AIDS patient.

At the end of 1994 he was admitted to the Academic Medical Centre of the University of Amsterdam because of a progressive dyspnoea. A very big tumour was found in his right lung extending in the mediastinum. A curative operation wasn't possible any more, so he got (palliative) radiation. Nevertheless there was a further growth of the tumour in all of the three lobes of the right lung.

He was dismissed from hospital with antiretroviral medication (AZT) and opioids (MS Contin).

When I made a visit last January he asked me about the possibilities for EU/AS. We discussed all possibilities and I explained to him the procedure. He had already arranged and subscribed to the declaration for assisted dying via his partner, who is also his witness.

Because of the pain, the medication was extended with other type of morphine in combination with amitryptilin. An oxigenator was placed at home and sufficient home nursing was arranged.

In February the pain and dyspnoea were unbearable; he wasn't able to sleep at night and was sitting upright. His situation is almost terminal and there aren't any treatment options left. Everything possible is done to relief his symptoms.

Last months we have spoken several times about EU/AS.

Mr Xxxxx is very determined and on 16 February I had also an extended conversation with his partner, his mother and his sister. I told the relatives what was going to happen.

The decision for EU/AS was made for the end of the month.

In the last two months I have spoken two times with his father, a Pastor of the Dutch Reformed Church, who is opposed to EU. We exchanged our views and I told him that I respect his values and beliefs and I asked him to respect the decision of his son. He wasn't able to tell if he would be present at the moment of dying. I asked him to do act in accordance with his conscience.

Conclusion

Mr Xxxxx has a terminal and non-treatable disease. The palliative options are exhausted.

He is mentally competent and has no signs of a mental disease. There is a (in January signed) declaration. The decision is made after full information.

Procedure

Yesterday my colleague Dr J D....., GP visited him for a second opinion and to see if all criteria were fulfilled. He phoned me after his visit that this is the case.

Drugs

Mr Xxxxx has asked for a liquid so he can drink it himself. The liquid with 9 grams of barbiturates is prepared today by the K.... Pharmacy (Mr Txxxxxxxx, pharmacist).

Last Phase

At 16.00 hours I was present at his home.

Mr Xxxxx was lying on his bed between his partner and his sister. The mother as well as the father were present. We had a short conversation and than I asked to Mr Xxxxxx: is what you really want'? He confirmed. He told me that he taken the premedication primeran (= *anti-emetic medication-hmL*).

I told him (again) that he was going to sleep in about five minutes after the administration of the drugs and that the sleep turned into a coma and that death should happen between 20 and 60 minutes.

I gave him the medication (in a cup) and he drunk it very fast. His favourite music was playing and during several minutes everybody said goodbye and caressed him till he died 20 minutes later.

Although his mother was crying there was a general relief that his suffering was over. The father thanked me, said "although we disagreed, I understand now what is going on. You have done a good job." An emotional moment.

I phoned the Coroner to make an appointment for the further procedure.

Henk-Maarten Laane

28 February 1995

APPENDIX 3

Example of Report of a Second Opinion for Euthanasia and Assisted Dying

H M Laane, GP, PhD, scen-consulting physician

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Muiden, 29-05-2004

REPORT OF A SECOND OPINION FOR EUTHANASIA AND ASSISTED DYING

Concerning: Misses M....., born 1966

Address

Amsterdam

I don't know Misses M, so I am independent in my conclusion.

Introduction

On 28 May 2004 I got a phone call from the SCEN to contact colleague L ..., GP in Amsterdam. I don't know colleague L..... at all.

Colleague L..... gave an extended explanation about her patient, the medical backgrounds and the reason for encounter. The medical records were send to my by fax.

Medical history

In September 2003 Misses M..... got severe symptoms in the abdomen. After consultation of the specialist the complaints were caused by pseudomyxoma peritonei caused by a carcinoma pseudomicosum ovarii.

She was operated two times in October followed by extensive chemotherapy. Nevertheless metastases were found several months later. The metastases grew very fast.

Last April also metastases were found in both lungs.

The major tumour mass in the abdomen compresses the bowels in a way that there is a complete discontinuity, a subileus. Medical intervention for this problem failed.

She can't eat anything at all. Only limited quantities of liquid. She has a continuous IV. In the last three weeks she lost over 8 kilograms.

There aren't any treatable options left.

The life expectations is one month at maximum.

Home visit

On May 28 I made an appointment by phone for a visit that same afternoon. Her partner will be present.

In the afternoon I visited misses M..... She lives in a very nice apartment on the third floor in the Centre of Amsterdam.

Although she lies almost the whole day on bed, she preferred to speak to me sitting on a table.

Social situation

Misses M.... owns a travel agency together with her partner.

She likes this job very much and has many friends and an extended social live.

From a former marriage she has a son of 5 years.

She is a very independent lady and she knows what she wants.

The suffering

She has a lot of pain because of the subileus. There is persistent nausea.

The suffering is a combination of the physical complaints and her loss of dependency, reason why she is dependant of others. She lies almost the whole day on bed, not able to do anything.

She feels her situation as unbearable, but she tries to go on as long as possible, also because of her son: "When I didn't have a child I would have asked for euthanasia a month ago."

Declaration

There is a declaration, signed 2004 April 12.

Summary

- There is a severe suffering, which can't be improved by medical treatment;
- The suffering is unbearable for Misses M.....;
- A living will is present and signed 2004 April 12;
- Misses M..... is compos mentis, I didn't found any sign of a mental disease;
- Misses M.... has told me her Will very clearly

Conclusion

To my conclusion all criteria of carefulness are fulfilled.

August 2004

Memorandum by Ian Maddocks

Emeritus Professor Ian Maddocks is a physician who has had 50 years of clinical experience in Australia, New Guinea and Africa. In 1988 he was appointed to what was probably the world's first Chair of Palliative Care at Flinders University of South Australia. He was Foundation President of the Australian Association of Hospice and Palliative Care (later Palliative Care Australia) and Foundation President of the Australian and New Zealand Society of Palliative Medicine. He retired from the Chair in 1999, and continues in active clinical practice in Adelaide, South Australia.

1. Palliative Care

Palliative Care physicians work with individuals confronting an imminent death from advanced illness to relieve discomfort of all kinds and to assist families through the time of dying and the subsequent time of bereavement.

2. Patient Responses to Advanced and Terminal Illness

2(i) The patients meet the threat of terminal illness in a wide range of ways. Some seek to deny its reality, and "fight" every inch of the way, accepting toxic therapies and seeking out alternative potions, extreme diets or faith-based healing in desperate attempts to prolong life. Referral for palliative care is anathema to them; it indicates a loss of hope, a "giving-in".

2(ii) Others are fearful of the discomforts of the terminal course, or disgusted by the physical and emotional changes they must cope with, and they "want out", to get it all over quickly. They also may be impatient with the offer of palliative care, seeing it as an unsatisfactory option, stringing out the dying process in unacceptable ways.

2(iii) In between those extremes are those who accept their changed situation with a fatalism, saddened by what is happening to them, and by perceived effect of the imminent loss on those who love them, but they display little anger, and are able to show an equanimity or even serenity in those final days. Others are clearly unhappy about what is happening, but look to their physicians for guidance and accept suggested treatments without much question. They will move on to the care of the palliative care team when suggested, and with no apparent reluctance.

2(iv) Among both the "fighters" and those who "want out" will be many who are accustomed to a high measure of control in their daily lives, and who find great difficulty in being subject to the inexorable decline in function and comfort now forced upon them. The more serene group, comprising persons who might be considered to have achieved a measure of "inner control", and will commonly include many very elderly persons who are able to say life has been good to them and that now they know it is time to go; and do not wish anything to make life last longer.

3. Responses Commonly Change or Evolve

Changes in discomfort, in projected prognosis, in responses to therapy (whether directed against the disease itself or to relieve symptoms) or in the family situation may lead to changes in how individuals respond to the threat of death from advanced disease. Some will initially promise to fight, but later feel that it is all pointless, going nowhere, and best finished quickly. Others, who have felt initially that the right course for them is to

seek a quick, comfortable and controlled death that will avoid the cost and discomfort and burden to others that terminal illness can entail, take new heart from some change in circumstance; they accept new therapies, and evince a new hope of staying on, perhaps for an important family event or anniversary.

4. Palliative Care Philosophy and Attitude

In that diverse and changing scene, Palliative Care seeks to proclaim a philosophy of care that seeks neither to hasten or shorten the dying process, but is, at the same time, "patient-centred", directed at responding appropriately and comprehensively to patient need—physical, emotional, spiritual. A conflict can arise between those two basic aims, when a patient wants to assume a measure of control that either delays or speeds up the timing of dying.

5. Reasons for Opposition to Assisted Dying Among Palliative Care Practitioners

5(i) Palliative care advocates have found a particular difficulty in the care of persons who ask for a deliberate and quick release from their situation of protracted dying.

5(ii) The reasons for that difficulty may be found firstly in the Christian traditions of Western society and their emphasis on the sanctity of life as a God-given gift, the ending of which divine providence alone should determine. The medieval monastic origins of the term "hospice", still used for aspects of palliative care programmes, support that tradition, as does the early work of the religious orders such as the Sisters of Charity, or the Little Company of Mary in the 19th century. More recently it has been fostered by the charismatic Christian leadership that has been so important in the establishment of palliative care in the British Isles and that has taught a consistent opposition to assisted dying, something that has become part of the usual advocacy by Palliative Care practitioners throughout the world.

5(iii) Medical tradition has also prohibited medical interventions to deliberately bring about death, as in the Oath of Hippocrates: "I will give no deadly medicine to anyone if asked, nor suggest any such counsel". This is modified in the Declaration of Geneva, adopted by the World Medical Association in 1948 which reads: "I will not use my medical knowledge contrary to the laws of humanity".

5(iv) There may also be for some practitioners of Palliative Care a feeling that advocacy for assisted dying carries an implied disregard of Palliative Care, a lack of knowledge or appreciation of the help it can bring. The "quick-fix" of assisted dying removes from the patient and the family the opportunity to complete their time together in ways that can celebrate love and patience and courage, qualities of great importance to any society.

5(v) Supporters of Palliative Care claim, and can illustrate with moving examples, that when delivered with skill and appropriate resources, palliative care can make the time of dying a powerful and positive experience for patients and the family members. They feel, with some justification, that there is a lack of awareness and familiarity among members of both the public and the medical profession with the benefits of palliative care, brought into play well before the terminal period. They feel that a widespread ignorance of palliative care is a factor driving the movement for legalising assisted suicide.

6. A Wish to Hasten the Process is Quite Commonly Expressed

I am involved in many circumstances in which both patient and loving family, recognizing that no improvement in the disease state can be anticipated, and aware of some discomfort (whether impaired clarity of cognition, pain, nausea, boredom, despair) that cannot be expected to be completely dispelled, express the wish that the process move faster. Sometimes this is a desperate plea—"If I were a dog you would shoot me, why can't you let me go immediately?"—more often it is a calm statement, a logical assessment of the unsatisfactory quality of current existence, and a wish that more active intervention was allowed. Commonly, there is an acknowledgement that the attending physician is not permitted to assist dying but included is an expression of hope that nothing will be done to hold back the approach of death.

7. Palliative Care Cannot Dispel all Suffering

Palliative care has been my full-time professional activity for 16 years. I do not pretend that my expertise can consistently relieve all discomfort, though I pride myself that I am often able to make a major difference, and engender a new hope that the further course of an incurable illness need not be one of great discomfort. However, there will often be situations where I feel unable to make such a major difference. I cannot reverse dementia, I am able to assist weakness and frailty only by suggesting helpful equipment and human support, sometimes for the most basic hygiene activities that cause great embarrassment. I cannot remove the burden

of the cost of care that sometimes erodes a family's resources in unforeseen ways. I can sometimes relieve pain or dyspnoea or extreme anxiety only by offering sedation that inhibits markedly the opportunity for continuing awareness and relationship.

8. A Request for Assisted Dying can be Rational and Logical

Therefore I recognize that a request for a quick release from an uncomfortable situation is quite often rational and not inappropriate. I sometimes will say to myself, "If I was in this situation, I would want to be removed from it quickly and painlessly".

9. Requests for Assisted Dying Will Increase

In my view, it is likely that the requests from patients and families for assistance with dying will increase, partly as a result of demographic change, making it more and more difficult for frail elderly persons to receive adequate care, partly through the increasing burden of health care costs on individual families, communities and nations (an enormous proportion of the health budget is being spent on care provided in the few short weeks prior to a death that is predicable) and partly through a greater public advocacy for the availability of deliberate assistance with dying.

10. Can Legislation Protect Against Abuse?

The question then is, "Can this be achieved through legislation in ways that avoid abuse, and protect those who are particularly vulnerable and at risk of being led to a decision, in which they have had little part, to end life quickly? Persons in the last phase of advanced illness can be confused, may have handed over authority for their care to a friend or family member who feels able to speak on the patient's behalf, but not always after asking the patient. I have had responsibility for the care of a person with advanced cancer who responded well to symptom control and was regarded as able to return home (which was her wish) only to find that the children had already sold the house without asking her permission. Family pressure upon doctors to suggest assisted suicide is conceivable, should legislation make it permissible under certain circumstances.

11. Is the Assisted Dying for the Terminally Ill Bill Adequate?

11(i) Specifically, is the Bill being proposed in the House of Lords one which could allow assistance with dying, but at the same time protect the vulnerable?

11(ii) The Bill requires that:

1. the request come from a *bona fide* resident, restricting foreigners from taking advantage of the provisions of the legislation
2. the person requesting assisted dying is regarded by two independent physicians (one a consultant) as suffering from a terminal illness (which I judge cannot be defined more precisely than appears in the definitions listed in the Bill)
3. the individual requesting dying is fully informed of diagnosis, prognosis and alternatives
4. the individual is judged by a consulting physician to be "suffering unbearably". I submit that this cannot be defined too rigorously; it should depend on open exchange between patient and physician, both acting in good faith. Suffering is more than physical suffering, but still accessible to objective judgement by an experienced physician.
5. the person have a right to tell or not tell family members. It is clearly desirable that the decision to undertake assisted dying be shared with those who can support the patient in this decision, but in some circumstances there is enormous family tension that is an important part of the "unbearable suffering". An encouragement to share the process with close family, and to recruit their acceptance and support of whatever decision is made would be potentially very helpful for the family. In some instances, however, a patient's declaration of a wish for assisted dying might exacerbate family tension in unfortunate ways, and a compassionate physician ought to be able to assess such circumstances.

11(iii) The need to create a document signed by independent witnesses (neither family nor attending physicians nor persons associated with a care institution housing the patient) and including a solicitor, seems to me an adequate protection against abuse.

11(iv) My personal view is that permission for doctors to assist death in particular circumstances and in carefully regulated ways is inevitable in the future, forced upon our societies by the reality of poor care for people born in our generation as we move into the aged persons category over the next 20 years. The proposed Bill is, my view, as well formulated as any I have seen, and deserves serious consideration.

12. Do I Have Any Reservations About the Bill as it Stands?

12(i) The bill limits the availability of assisted dying to persons who are competent and of sound mind. There is no provision for the decision to accept assisted dying being made in advance of (say) the onset of dementia, nor of authorising another person to make the decision to proceed with assisted dying should the patient be deemed to be not competent.

The exclusion of incompetent persons seems to me to be an important provision at this stage. I believe that most societies will be forced in time to consider further legislative measures that allow dying by advanced directive or by an authorised substitute decision-maker, but theological, public and medical opinion will need much deeper consideration and extensive discussion before accepting any move to allow and implement such additional measures.

12(ii) I look for some recognition of the need to give time for adequate discussion between physicians, patient, and family members. No hasty assessment from the foot of the bed or through a quick perusal of the notes and some consultations in the corridor will suffice. It is a most important contract between physician and patient, and it calls for most serious and careful medical assessment that will hopefully encourage the best honest exchange, mutual respect among the parties and sympathetic concern for the patient's wellbeing on the part of each and every physician who may be involved. It is in that context that the offer of alternatives should be made, not seeking to influence a decision, but listening very carefully for all the nuances and associations that may accompany a request.

20 August 2004

Memorandum by Professor Roger Magnusson, Faculty of Law, University of Sydney

1. I am an Associate Professor in the Faculty of Law, The University of Sydney, Australia. I am the author of *Angels of Death: Exploring the Euthanasia Underground*, published in the United Kingdom by Yale University Press (2002). I am also the author of a short article entitled *Euthanasia: above ground, below ground*, that appeared in the *Journal of Medical Ethics*, October 2004, 30: 441–446, published by the British Medical Journal Publishing Group. This article expands on issues raised in this submission.

2. I am one of a very few researchers to have conducted interview-based research into the practice of illicit or "underground" euthanasia. *Angels of Death* presents data from interviews I conducted with health care workers in Sydney, Melbourne and San Francisco, who worked extensively with patients with HIV/AIDS. The contribution that research into "underground euthanasia" can make is to provide a window on hidden practices, exposing the kinds of things that occur. This research is also important because it indicates that euthanasia practices will continue to occur whether they are prohibited or not. The only issue is whether Parliament wishes to try to regulate these practices, or to leave them to the "underground".

3. The Select Committee is likely to hear many passionate, well-motivated arguments about the dangers of a "slippery slope". I do not disregard these risks (see *Angels of Death*, p 260ff), but they should also be balanced against the realities of "underground euthanasia", as practiced in countries where assisted death is prohibited. Currently, euthanasia is hidden and practiced in an idiosyncratic manner without meaningful constraints. Chapters 10–11 of *Angels of Death* (and the first part of my accompanying article) detail some of the harms to society that result from a policy of prohibiting assisted death. I argue that "underground euthanasia" (which surveys show is relatively common, although practiced only by a minority of doctors) embodies the very opposite of those attributes which characterise "medical professionalism". In the euthanasia underground, there is no specialised training: the criminal law ensures that participants remain ignorant about what is needed to achieve a gentle death. This results in "botched attempts": doctors who only manage to put their patient into a coma and end up suffocating or strangling the patient in order to "finish the job". "It took four or five hours", said one doctor. "It was like Rasputin, we just couldn't finish him off". (This was a respected professional, with a good media profile). "I tried insulin, I tried just about everything else that I [had] around and it just took forever . . . [It was] very hard for his lover. So I um sort of shooed the lover out of the room at one stage and put a pillow over his head, that seemed to work in the end [laughs, nervously] . . . That was one of the worst [clearing throat] one of the most horrible things I've ever done".

4. Accountability is also absent when assisted death is carried out surreptitiously. Professional medical bodies know what happens but for the most part they turn a blind eye. In the "underground", there are no accepted norms or principles guiding involvement: none of the safeguards mentioned in ss 2–5, 8, 13–14 of the proposed legislation. Instead, participation is shrouded in secrecy and deception: doctors lie on the death certificates, they create false "paper trails" so as to generate a plausible clinical case for larger doses of medication that are then administered as an overdose. There is evidence of casual and precipitative involvements: one doctor performed euthanasia on a patient on the first occasion they met, despite concerns from friends and family that the patient was depressed. Another doctor, called out in the middle of the night to "finish off" a patient whose suicide attempt had failed, told me: "I realized [he] was not going to survive this . . . I might as well speed it along. I think also because it was four o'clock in the morning, *I had a cold and I felt dreadful and I just wanted to get out of there*". Examples could be multiplied.

5. *Angels of Death* puts these issues on public record. These are the costs of prohibition, and they must also be weighed in the balance. The *Assisted Dying for the Terminally Ill Bill*, by providing a statutory procedure for assisting the dying of terminally ill suffering people, aims to re-regulate these practices. The Bill provides a process through which a patient's desire to die can be rationally assessed. It contains safeguards, which are absent when euthanasia is practiced surreptitiously. The choice that Parliament faces is not between permitting euthanasia to occur or not permitting it. It is between making it visible or allowing the "underground" to continue. The challenge is to weigh the risks of legalisation against the harm that underground euthanasia currently causes. I do not pretend that it is an easy decision. These policy questions are considered in more depth in the accompanying article and in Chapter 13 of *Angels of Death*.

6. The Select Committee will likely hear many assertions about euthanasia as practiced in the Netherlands. I would submit to your Lordships that our ability to castigate the Dutch about their rates of non-compliance (with the statutory criteria that are pre-conditions to lawful involvement in euthanasia, under Dutch legislation) comes courtesy of the relative transparency created by the Dutch policy of legalisation. If we wish to make ambit claims about slippery slopes, it is only fair to point out that the reporting rate for euthanasia in Britain, Australia, and most other countries, is *zero*. In light of that, even partial compliance with statutory safeguards may represent an improvement on the kinds of clinical decisions that currently occur in secret. As one interviewee said, if euthanasia is to be practiced, "it needs as much recognition as a tonsillectomy; if you're going to medicalise it and give doctors all this power, then it needs to be subject to scrutiny, like a surgical audit", in order to protect patients from mentally disturbed, impaired or alcoholic doctors. I would submit that the interests of terminally ill patients are sufficiently important that Parliament should seek to re-regulate the "euthanasia underground", in order to protect patients at the time that they are most vulnerable.

7. One final brief comment. The Select Committee may hear some opposition to legalization from doctors themselves. While the literature demonstrates, empirically, that a substantial number of health care workers do, in defiance of the law, assist patients to die,[147] health workers are also quite fragmented in their attitudes towards assisted death. Some oppose it for moral reasons. Others oppose it because they don't want the law to interfere with their "clinical prerogative". One interesting finding that emerged from some of the interviews I conducted was that some of those who were most heavily involved in providing covert assistance did not—counter intuitively—want euthanasia to be legalised. One interviewee, a "highly active" nurse, told me that she feared that legalisation would involve too much "red tape" and asked "why should doctors be the only ones who can make these decisions?" The doctor who spoke about "Rasputin" (above) said: "I'd be afraid that if [euthanasia] were legalized that there would be some controlling mechanism which might make it extraordinarily difficult for it to occur . . ." I would submit that if doctors are going to become involved in assisting the dying of their patients, there should be regulation. Despite the skepticism of the medical profession about law and regulation generally, assisted dying is most certainly an area where the law ought to meddle. Anyone who thinks otherwise simply has no idea how underground euthanasia is really practices.

16 August 2004

[147] In a 1994 study of 312 British doctors, Ward and Tate reported that 124 of 273 doctors answering the relevant question (45 per cent) had been requested by a patient to hasten death; 12 per cent of these respondents complied: Ward B J, Tate PA, Attitudes Among NHS Doctors to Requests for Euthanasia. BMJ 1994; 308: 1332–4. Keown also reports that a survey of 1,000 Scottish health care workers found that 4 per cent had assisted suicide either by providing drugs or advice: see Keown J. *Euthanasia, Ethics and Public Policy: An Argument Against Legalisation*. Cambridge: Cambridge University Press, 2002, p 61. For tables summarising Australian and United States surveys, see Magnusson RS, *Angels of Death: Exploring the Euthanasia Underground*. New Haven and London: Yale University Press, 2002, pp 39–42.

Memorandum by Yvonne Yi Wood Mak, Medical Officer, Bradbury Hospice, Hong Kong and Glyn Elwyn, Professor in Primary Care, Primary Care Research Group, University of Wales, Swansea Clinical School

VOICES OF THE TERMINALLY ILL: UNCOVERING THE MEANING OF DESIRE FOR EUTHANASIA

NOTE:
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ABSTRACT
This study aimed to gain deeper understanding of the meaning of desire for euthanasia. An hermeneutic approach was undertaken, using a purposively selected sample of advanced cancer patients who desired euthanasia while receiving palliative care. Unstructured interviews were conducted with six participants, which were audiotaped, transcribed and analysed. This approach allowed in-depth exploration and interpretation of the patients' lived experience. The findings illustrated a timeline from previous wellness to approaching death with five major themes: (1) reality, (2) perception, (3) anticipation, (4) desire and (5) holding environment. The desire for euthanasia is not confined to physical or psychosocial concerns relating to advanced cancer, but incorporates hidden existential yearnings for connectedness, care and respect, understood within the context of the patients' lived experience. Euthanasia requests cannot be taken at face value but require in-depth exploration of their covert meaning, in order to ensure that the patients' needs are being addressed adequately.

Keywords: euthanasia; existential; hermeneutics; palliative care; personhood; suffering.

INTRODUCTION

There have been countless debates among medical professionals, ethicists, academics, politicians and pro-euthanasia campaigners on the legal and ethical aspects of euthanasia.[1-3] Although palliative care has been argued as the alternative to euthanasia,[4] a minority of terminally ill request hastened death despite receiving palliative care.[5-8] Euthanasia would seem a rational option in dealing with unrelieved suffering, once all other medical interventions have failed.[9 10] But a controversy remains in both ethical and clinical circles as how best to respond. This leads to arguments about clinical efficacy and questions how society and medicine view human worth and suffering. Some medical professionals have responded by focusing on respecting patient autonomy, assessing mental competence and determining legal guidelines.[9-12] Indeed, euthanasia and physician-assisted suicide have become recognised medical practice in the Netherlands, physician-assisted suicide in Oregon and euthanasia in Belgium.[8 11] Wary of medically assisted death, palliative care experts continue to advocate a holistic approach to alleviating suffering.[4 13-16]

But the fundamental question is, "Why do patients desire euthanasia?" From research evidence, reasons have included pain, functional impairment, dependency, burden, social isolation, depression, hopelessness and issues of control and autonomy[5 7 17-20] These data, however, have been derived primarily from perspectives of healthcare professionals, relatives and the public. Surprisingly, data from patients' perspective is scarce. A few studies have explored patients' intentions towards their desire for death, but those patients were neither terminally ill nor opting for hastened death.[18-20] Patient attitudes in response to hypothetical scenarios might not correspond to actual reactions of those who are terminally ill or wanting death.[21] In addition, studies have been primarily quantitative, overlooking the complexity of the subjective experience.

Given the scarcity of research that explores euthanasia requests from a patient perspective (Table 1) and the fact that the will to live in the terminally ill is known to fluctuate during the course of illness,[22] legalising euthanasia is at best, contentious, and at worst, unreliable. It is vital to investigate this area in more detail. We aimed to explore the meaning of desire for euthanasia, gathered from advanced cancer patients who had expressed such a wish.

Table 1

LIMITATIONS OF RESEARCH STUDIES ON EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE

Methodology	*Limitations*
Research focus	Attitudes of healthcare professionals, relatives and the public rather than the reasons for desiring hastened death according to the patients

Study design	Primarily quantitative overlooking the patients' subjective experience and contexts Researchers rather than the patients determined the agenda
Sample	Not necessarily involving the terminally ill or those who desire for hastened death
Data collection	Use of questionnaires, self-report instruments and hypothetical situations Structured interviews rather than allowing the patients to express their experience according to their own agenda

Methods

We required a research approach that would examine in depth the innermost voice of patients who desired euthanasia, without neglecting their subjective experiences and contexts. But as this group was considered "vulnerable", we had to ensure that the methodology was compassionate and adhering to high ethical standards. And as we wanted to understand "why" patients desired death, we chose an interpretive approach. With these considerations in mind, we designed an in-depth qualitative study by applying the philosophy of hermeneutics. The methods have been described in detail elsewhere.[23] This approach focused on understanding and interpreting subjective experiences within context through in-depth exploration of text, such as unstructured patient interviews. Ethical approval was obtained from Bradbury Hospice Research Education Ethics Committee.

Setting and recruitment

The study was conducted in a palliative care unit in Hong Kong over a four-month period in 2000. This unit consisted of a 26-bedded hospice and a comprehensive home care service with a caseload of approximately 150 Chinese patients with advanced incurable cancers. We identified participants by purposive sampling, recruiting only those palliative care patients who expressed a "desire for euthanasia", defined as individuals who by their own initiative, had stated a desire or request for their doctor to terminate their life. We excluded patients who were confused, dying, unable to communicate, too weak or emotionally distressed to be interviewed.

Data collection

YM conducted unstructured audiotaped interviews with each participant, lasting approximately 20–60 minutes. The unstructured format of interviewing ensured the patients' agendas were fully represented and the use of dialogue was a sensitive way of obtaining data. She established rapport by using open questions, followed by queries such as, "You mentioned earlier that you had desired help in ending your life. Can you tell me more?" Patient medical records were read in order to contextualise their accounts of lived experience.

Dual role as researcher-physician

YM had a dual role as a researcher-physician during this study. There were obvious potential biases, whereby patients might feel obliged to participate or modify their replies in an attempt to please their doctor. Therefore consent procedures emphasised that patients were under no obligation. They were reassured that they could talk openly without any detrimental consequences on their future care. An independent team member who had no conflict of interest verified their assent and then reviewed them after the interviews to ascertain that they were free of distress.

Data analysis

YM formulated a preliminary understanding of why patients desired euthanasia before proceeding to the data collection and analysis. This included the review of medical literature, previous pilot study and case reports of patients with euthanasia requests at Bradbury Hospice, and reflections of her personal stance regarding euthanasia.[23] This "pre-understanding" served as an initial interpretive framework. After conducting and transcribing each interview, YM read the transcripts several times to develop an impression of the "whole". She then extracted "parts" from the transcripts, which contained significant phrases relating to the experience of euthanasia. She reflected on the interrelations between the "whole" and the "parts", and formulated the data into codes, categories and themes. As she reflected on the data, the data generated more questions to challenge her initial interpretive framework. She validated her pre-understanding with the findings and discarded any pre-understanding that was unsupported, thereby renewing her interpretive framework. As she analysed more transcriptions, the interpretive framework was further refined. The data analysis therefore involved a process of continual reflection, questioning and validation, occurring between the evolving interpretive framework and successive transcriptions. GE verified the occurrence of themes with the original

transcripts. A palliative care nurse, a psychologist and pastoral care worker from the Bradbury Hospice multidisciplinary team, together with a UK palliative medicine consultant, reflected on the fittingness of findings in relation to their clinical context.

Findings

We identified seven patients according to the selection criteria. One of them gave cues such as "not having much to say" and "feeling tired", suggesting a disinclination to take part, and this was respected. The remaining six patients' details are shown in Table 2. The findings illustrated a depth of meaning, ranging from overt physical and functional concerns to covert psychosocial and existential needs, along a timeline from previous wellness to approaching death. Data analysis revealed 18 minor themes, categorised into five major themes: (1) reality, (2) perception, (3) anticipation, (4) desire and (5) holding environment. The occurrence of minor themes mentioned by the participants is outlined in Table 3.

Table 2

PARTICIPANTS' DETAILS

Participants	*1*	*2*	*3*	*4*	*5*	*6*
Age (years)	61	73	54	71	70	83
Sex	Female	Female	Male	Male	Female	Male
Malignancy	Neuro-endocrine	Lung	Osteosarcoma	Kidney	Leiomyosarcoma	Lung
Hospice service	Inpatient	Home care	Inpatient	Home care	Inpatient	Home care
Functional status (%)*	40	50	40	70	70	60
Occupation	Retired manual worker	Retired Amah	Bus-driver	Retired Sailor	Manual worker	Retired manual worker
Social support	Good	Poor	Good	Poor	Good	Poor
Depression†	—	—	Yes	Yes	Yes	—
Bereaved	—	—	—	—	—	Yes
Timing of first euthanasia request after starting hospice service	Within 1 week	Within 1 week	Within 1 week	9 months	Within 1 week	6 months
Duration from first euthanasia request to death	3 weeks	9 months	6 weeks	5 weeks	2 months	1 month

*According to Karnofsky Performance Scale
†According to Endicott's criteria for clinical depression

Table 3

OCCURRENCE OF MINOR THEMES IN PARTICIPANTS 1–6

1	*2*	*3*	*4*	*5*	*6*	*Minor Themes*
+	+	+	+	+	+	1 Inevitability of death
+	+	+	+	+		2 Hopelessness
+	+	+	+		+	3 No longer who I used to be
+	+	+	+	+	+	4 Suffering
+	+	+		+	+	5 Burden
+	+	+	+	+	+	6 Witness
	+	+	+			7 Inadequate knowledge
	+	+	+	+	+	8 Unskilful communication
+	+			+	+	9 No one would understand
	+	+	+	+		10 Misconceptions
	+	+				11 Fantasies
	+	+		+		12a Fear and anticipation of increasing suffering
	+	+	+		+	12b Fear and anticipation of increasing dependency
		+		+		12c Fear and anticipation of increasing burden
	+	+	+		+	12d Fear and anticipation of future lack of care
+		+	+	+	+	13 Passive resignation to bad destiny
+	+	+	+	+	+	14 Good death
+	+	+	+	+	+	15 Attention to needs
	+		+		+	16 Significant others to care
+	+	+	+	+	+	17 Good quality healthcare professionals
+		+		+		18 Supportive significant others

Reality of Disease Progression

Participants were aware of the inevitability of death. An incurable disease and progressive deterioration meant hopelessness. They were no longer who they used to be.

> *"This sort of disease ultimately leads to death. I have to walk that path."* (1)
>
> *"Not much hope, nor would there be any miracles . . . You doctors can't help when the patients deteriorate and then drop dead . . ."* (4)
>
> *"I used to be the sole breadwinner, but suddenly I couldn't work . . . Instead, they have to care for me."* (3)

Perception of Suffering for Self and Significant Others

The perception of suffering was multidimensional ranging from physical, functional, social and psychological to existential issues.

> *"To have pain and also breathlessness, that would be really terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering . . . The social situation is suffering . . ."* (2)
>
> *"I can't move, just lie here . . . feeling like a vegetable . . . a useless person . . . needing people to feed me."* (3)
>
> *"I just don't want to endure these psychological effects . . . So much suffering . . . I have had the pain for four years . . . So many psychological effects . . . How can I bear it?"* (1)
>
> *"Wish to live but can't live; wish to die but can't die."* (6)

Participants perceived that they were causing suffering for others. They felt a sense of burden, having witnessed the impact of their cancer on the well being of their significant others.

> *"For them to see me in pain is suffering. To see the family rushing around is so suffering . . . That makes me suffer . . . They spend a lot of money . . . I fear the rushing around would make her* (wife) *ill, burdening her."* (3)
>
> *"My husband has no job . . . Wouldn't you agree that my husband is suffering? When I got the cancer, my daughter asked for leave for a month, to allow her dad not to give up his job . . . I didn't want him to resign. My daughter had no option but to get no pay leave for a month . . . Her father then resigned. Who would want to him now? He's already in his sixties."* (1)

Anticipation of a Future Worse than Death Itself

Participants had inadequate knowledge about their prognosis and anticipated a future by recounting their observations of other patients in acute hospitals with unbearable pain, helplessness and indignity.

> *"I haven't been in hospital before. I wouldn't know the facts. I haven 't been ill before."* (3)
>
> *"I've seen other patients yelling in pain and they were suffering . . . so intolerable . . . Just to hear them was very suffering . . . It must have been so unbearable to have to yell like that. If they could endure it, they wouldn't have yelled."* (3)
>
> *"Someone with a tube sticking up the bottom, a tube sticking into the nostrils, another somewhere else. I mean, what for? Can you save them?"* (4)

Participants perceived the doctors' communication to be unskillful, lacking clarity and reassurance. Time allowed for decision-making was inadequate.

> *"Just one sentence can hurt me, making things even worse . . . Really bad . . . When I need someone to help me, they just hurt my self-esteem . . . the occasional sentence or even half a sentence. Even a hundred good words wouldn't make up for that one bad word . . . A blunt rejection and a more subtle reply can make a big difference . . . very important . . . very suffering . . . I was right but they said I was wrong . . . What was worst was that I had to admit to being wrong and agree with them."* (3)
>
> *"They suggested radiotherapy and in fact, I didn't know what radiotherapy was about but within a week, I had four doses of treatment."* (4)
>
> *"I asked the doctor, 'Doctor, do people with cancer get a lot of pain?' He answered, 'In the majority they do.' Then I asked, 'Is it possible not to be like that?' He answered, 'Possible, I suppose.' Ah . . ."* (6)

Participants perceived that no one could understand their suffering and felt that it was pointless to express their needs. They misconceived that pain would be ultimately inevitable and uncontrollable.

> *"I have sought many doctors. In many aspects, they don't understand, right? Only I'd understand."* (1)

> *"If you get cancer, you'll get pain. Cancer is a painful disease. It'll just get more and more painful."* (2)

Participants imagined a future with further tumour growth, treatments and complications. They feared increasing suffering, dependency and burden, and future lack of care. They were passively resigned to their bad destiny with helplessness and powerlessness.

> *"It'll be extremely terrible. It'll be coming up from here, coming up from there, just everywhere. I mean the complications and that would give me so much pain and suffering. I anticipate the future would be like this. Very severe, very scary when I think about it."* (3)

> *"In the future when I can't manage, I would feel very bothersome and very suffering as if I'm really burdening them. I'm afraid of having others to serve me."* (2)

> *"Some don't have loved ones around. Others have nobody to care for them. Others have relatives but they don't care . . . I only have one daughter. If she doesn't help, who is going to help? . . . So miserable that I cannot express it in words."* (6)

> *"Whether it gets better or not, it's destined. I'll wait to die. There's no way out even if the pain returns. It'll come when it may. I'll just go along with the pain and die. Nothing would help."* (5)

Desire for Good Quality End-of-Life Care

Participants desired an escape in order to relieve the suffering for themselves as well as their significant others. They hoped for holistic care, namely pain and symptom control, maximizing functional potential, psychospiritual support and relieving the burden of their relatives.

> *"You want to be cured, that isn't possible but at least give me back some of my energy."* (4)

> *"I hope everyone can accept it . . . Most important is that my family wouldn't be heartbroken. If there were no suffering, I would like to see them for longer."* (3)

Holding Environment

Participants desired connectedness, care and respect from healthcare professionals but more so from their significant others. Family and friends provided them with a sense of intimacy and relatedness. For participants 1, 3 and 5, their suffering was more tolerable and continual existence meaningful.

> *"Coming here* (hospice) *has helped me a lot, at least spiritually and in every other aspect. People comfort and reassure me and so it doesn't feel so intolerable."* (3)

> *"The doctor is very kind . . . so gentle and willing to help . . . She knows how patients feel and is full of compassion. When she sees us suffer, she also suffers . . . She can handle her job well . . . The pain is gradually getting better. . . Having the opportunity to talk to her is a blessing . . . Having her to look after me, I feel more at peace."* (5)

> *"There is meaning, because I realise so many people are showing their care and concern. It's totally incredible. I am very touched by that . . . So many people supporting me . . . totally unexpected."* (3)

Participants (2, 4 and 6) with poor social support or conflicting family relationships expressed the desire to be cared for by their significant others.

> *"In the hospice, definitely enough care. That's their job. But I have only one daughter . . . I need her to care for me . . . I need her to care for me!"* (6)

> *"Are there any real good friends? Yes, there are, not that there aren't. But that's only once in a while. But for others to show concern daily, you can't expect much . . . I wanted to find a companion as I was getting old . . . But little did I know it was better not to find one. So I have no children . . . not a relative."* (4)

Discussion

The desire for euthanasia cannot be interpreted at face value. Its meaning is not confined to the reality of physical disintegration or suffering from the effects of cancer, but includes fears and existential concerns with desires for connectedness, care and respect, understood within the context of the patients' whole lived experience.

To our knowledge after a detailed literature search, this is the first study to explore in-depth the views of advanced cancer patients who have desired euthanasia using a qualitative method. The analytic framework and interview process of interpretive phenomenology was aligned with our aims and ethical considerations,

given the need for an inductive synthesis and sensitive data collection. Interviews were short and repeat interviewing difficult, owing to the participants' debility and limited life expectancy. Only six patients were recruited due to the time constraint of this study as part of a MSc course, but this sample size was acceptable for in-depth studies of this nature. Although we do not attempt to generalize from these interviews, we believe that our findings are transferable to other terminal care settings. The bias generated by the researcher's dual role as a researcher-physician is stated openly. The requirement to formulate a statement of pre-understanding prior to data collection and analysis contributed to the methodological rigour of this study.[23]

The thematic analysis corresponded to the concept of personhood. Cassell emphasizes that clinicians need to explore the complex nature of suffering according to the patient's personhood in order to diagnose suffering.[24, 25] The sense of existence in relation to the world of relationships, roles and rights within the person's unique context are also relevant dimensions of one's personhood other than the body, mind and spirit. Threat to any of these issues would lead to a reduced sense of wholeness. A qualitative study on the desire for euthanasia and physician-assisted suicide in HIV patients revealed similar findings relating to the loss of personhood, namely bodily disintegration and loss of relatedness to the community.[26]

Issues of burden were prevalent in this study. Participants who were supported by their significant others felt a sense of burden. Chinese patients are family-orientated and would be willing to sacrifice their own personal interests for the benefit of their family.[27] Their loss of serving role gave them a sense of worthlessness and suffering having to burden others. On the other hand, those participants with poor social support desired care and connectedness. Elderly patients also perceived themselves as a burden to the younger generation; yet they expected and yearned to be cared for. Lo quotes,

> *"According to the Confucian social version, the good society is one, through extensive support network, in which 'widows, orphans, the childless, the disabled, and the sick are to be well taken care of 'Further more the elderly were highly esteemed in ancient China . . . Hence the sick elderly were not allowed to be seen as 'burden to anybody at all'."*[28]

Thus one could argue that in a culture that values utility and family obligations, legalising euthanasia on the grounds of burden could lead to moral disintegration. Social isolation has also been found to correlate with the desire for hastened death in the western culture,[5, 18, 29] but others have argued that the need for control and autonomy were more significant factors.[30]

The minor themes related to "anticipation" provided insight into the patients' inner world and perception of medical care, illustrating how these factors could mould their anticipation and fears of a dying process worse than death itself. Witness of poor care and unskillful communication have been reported but not emphasized as contributing factors to patients desiring hastened death.[18, 21, 29, 31, 32] Patients who have witnessed others in suffering might anticipate the same dying trajectory for themselves. Patients with HIV and serious chronic diseases, who have experienced what perceived to be undignified deaths, were significantly more likely to consider physician-assisted suicide.[18, 21] Other studies have shown that inadequate information, excessively candid explanation, hasty decision making and phrases such as "no more active treatment" and "transfer to hospice" contributed to the patients' suffering, hopelessness and experiences of a bad death.[29, 31, 32] All these factors could govern their rationale for wanting hastened death.

The natural flow of the interviews revealed a depth of meaning in the participants' desire for euthanasia (Table 4). They progressed from overt comments about physical disintegration and functional impairment as reasons for desiring death to deeper psychosocial and hidden yearnings for care, connectedness and respect.

Table 4

DEPTH OF MEANING OF DESIRE FOR EUTHANASIA

Depth of Meaning	*Major Themes*
[Overt]	I. Reality
Physical/Functional	— Disease progression
	— Inevitability of death
	— Physical deterioration
	— No longer who I used to be
[Deeper]	II. Perception
Psychosocial	— Current suffering for self and significant others
	III. Anticipation
	— Increasing suffering
	— Increasing burden
	— Increasing dependency
	— Future lack of care

[Covert]	IV. and V. Desire and Holding Environment
Spiritual/Existential	— Being cared for
	— Connectedness
	— Respect

Existential suffering has been least researched. Morita and colleagues conducted a literature search on existential distress, which they classified into 13 categories.[33] Categories such as meaninglessness in present and past life, loss of social role functioning, feeling emotionally irrelevant, dependency, burden, separation grief and "why me?" corresponded to our findings. We postulate that current clinical mandate in dealing with euthanasia requests might not have addressed underlying existential concerns adequately, thus leading to unrelieved suffering.

The lack of previous analysis from the patients' perspective should temper the call to legalise euthanasia. The Royal Dutch Medical Association judges that existential suffering should not be a justification for euthanasia.[34] As this study revealed many hidden existential concerns, the desire for euthanasia cannot be taken at face value. The clinical mandate requires a paradigm of care beyond the biomedical model, by re-orientating to the patient's lived experience. We should not focus on our patients' mental competency in their decision-making, but rather our professional duty in ensuring competent existential care, by exploring the covert meaning of their desire for euthanasia (Tables 5 and 6). The lack of previous evidence in this pivotal area of palliative care indicates the need for further work in different cultural contexts.

Table 5

PROPOSED CLINICAL FRAMEWORK IN DEALING WITH PATIENTS DESIRING DEATH

Themes	*Exploration from the superficial to hidden agenda*
Reality	Understand patient's unique personhood
	"Who I used to be"
	Effects of cancer and major life events on the integrity of personhood
	Losses of roles, lifestyle, dreams and aspirations
Perception	Explore perceived present—"Tell me about your suffering"
	Explore current suffering for patient and their significant others
	Explore multi-dimensional of suffering
Anticipation	Explore perceived future
	Explore what patients have seen, heard and experienced in terms of care
	Elicit any misconceptions
	Explore fears and fantasies regarding disease trajectory
Desires	Explore hidden yearnings—"What do you really want?"
	Explore hopes and dreams
Holding environment	Identify a holding environment congruent with patient's unique personhood
	Identify significant others
	Define individual sense of belonging

Table 6

PROPOSED MORAL FRAMEWORK FOR CLINICAL INTERVENTION IN PATIENTS DESIRING DEATH

Holding environment	*Clinical mandate*
Connectedness	Presence
	Genuineness
	Trustworthiness
	Active listening and empathy
	Acknowledgment
	Attention to non-verbal communication and cues
	Non-abandonment
Care	Holistic carer with knowledge, skills and virtues
	Tailor-made individualised holding environment
	Address needs/concerns and prioritise actions
	Compassion—willingness to "walk" with the suffering patient
	Adequate explanation

Holding environment	*Clinical mandate*
	Correct misconceptions about diagnosis/treatment/prognosis
	Reassurance about commitment to care
	Pain and symptom control
	Maximise functional potential
	Social support to reduce burden of significant others
	Help patients surrender to the physical/need for control and independence
	Psychological re-framing
	Empower the spiritual dimension
Respect	Sensitivity
	Prudence and practical wisdom
	Promote self-worth—"You're still you."
	Explore meaning for continual existence
	Encourage expression of needs however unrealistic they might seem Adequate information according to patient's pace
	Negotiate with patient in setting realistic goals of care

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Contributors

YM, who is the guarantor for the study designed the study, collected and analysed the data. GE supervised the MSc in Palliative Medicine to which the work contributed, provided advice about design and analysis and helped write the article.

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Letter from Baroness Masham of Ilton DL

I greatly welcome the opportunity to share my views on the Assisted Dying for the Terminally Ill Bill with the Committee.

I must declare a personal interest in this subject.

I had a serious accident nearly 46 years ago. I was taken to the casualty department of an accident hospital with a fractured spine, a suspected fractured skull, several fractured ribs, internal hemorrhage and semi-conscious.

The doctor on duty, after examining me, said to my fiancée (who later became my husband), "If she lives through the night she will never move again." The view of my attendant physician was that I was suffering without any reasonable prospect of cure from a distressing physical disability and he may well have thought it intolerable. Under the cover of a Bill like this, that doctor might well have let me die.

I do not know how one measures pain. I know that in the first three weeks of injury my pain was indescribable. When one is suffering and sweating pain there is somehow a light at the end of the tunnel, and that is the light of hope. Even with patients with a terminal condition who should, and generally do, have drugs to make them comfortable, the aim should be where there is life there is always hope for a cure.

It is encouraging that there are many new hospices being set up and of the increasing concern towards the care of the dying. If a patient can die in calm dignity it is a relief for all concerned.

Clause 15 of this Bill makes provision for pain relief medication. However, good symptom control is already lawful. Morphine and other similar drugs measured for pain control, and even sedatives in the terminal phase of illness, do not shorten life. There will always be a last dose of course, but it is the disease that has killed the patient. One does not need to kill the patient to kill the pain.

I am sure that it is not the intention of Lord Joffe to frighten people, but all sorts of complications occur with some legislation and already this Bill itself will have caused a great deal of harm. The Sponsor of the Bill continues to stress about so called "safeguards" contained in his Bill. However, there is no system of "safeguards" that can detect the hidden pressures and strains from family (who will quite often have much to gain financially), friends and even carers that may drive a disabled person to seek an assisted suicide. There is added pressure because of the expense and difficulty of providing long term care for severely disabled people. Rather then ensuring the right to die, I strongly believe that this Bill will quickly translate into a duty to die for disabled people.

This Bill is contrary to the ethical principles of most medical and nursing staff and it would be morally wrong to enforce this pressure on anyone. For example, the Royal College of Nursing and the British Medical Association have both stated that they are against the Bill. Euthanasia is illegal and the Royal College and the British Medical Association do not condone it. The Royal College have stated that they believe that the practice of euthanasia is contrary to the public interest, to nursing and medical ethical principles as well as patients' civil rights.

Conclusion

The key principles of this Bill are so dangerous that it is unacceptable for them to be even considered as public policy, let alone being introduced into Parliament as legislation.

I submit that the Committee should examine closely how such policy developments in the area of assisted suicide has gone so astray as to arrive at such unethical proposals.

2 September 2004

Letter from Professor T S Maughan

I am writing to you to express my very great concern about the possible legalisation of assisted dying and to put my opinion before the Committee.

As a Cancer Specialist working at the cancer centre in Cardiff, my everyday work brings me into close contact, often after prolonged relationship, with patients facing their death. It is my experience that the vast majority wish to live, though they come to terms with their impending death and often face it with great courage and peace. The involvement of palliative care services is of immense help to many patients who are suffering distressing symptoms. It seems however, that there are some patients, in my experience a very small number, who have made a clear and determined decision to end their lives as in the cases of Diane Pretty and Reginald Crew. The Joffe Bill seeks to legitimize this process in order to extend the autonomy of these individuals. I am much more concerned by two other groups of patients who are equally vulnerable yet are likely to be much more at risk if this goes ahead.

The first are the many patients—with cancer and indeed any serious disease—who go through a period of severe depression or a sense of hopelessness, either at diagnosis or at some point in their disease journey. It is these patients who have asked me for a lethal injection. Yet in every case I have observed that this episode of depression is self limiting and patients come through to accept and work with their new situation—often to address important issues with their families which would otherwise have been unresolved. If this Bill was approved, I suspect many of these patients would be helped to die, a decision they would have regretted once that episode of depression is past, just as they have looked back on their request with chagrin. This correlation of depression with a desire to die has been reported in most publications on this issue. The Bill calls for a psychiatric opinion if the physician considers the patient not to be competent. That will not be an adequate defence—these patients are at that point reflecting their true desires—the point is those desires are often relatively short lived and reverse with support, good palliative care and where people are treated with dignity. The first patient to receive euthanasia in Northern Territories Australia was just such a patient and I am sure it would happen here, repeatedly.

The second group are those who feel themselves to be a burden, as many do in our burdened Health Service and increasingly disjointed society. They themselves want to live, but believe themselves to be placing an intolerable burden on loved ones. It may not be that they are being pressured, but they feel a burden. There

is no doubt that there is much suffering at the side of a loved one who is dying, it can be a terrible place—it's the pain of anticipated loss—and for the person who is dying the added sense of guilt because they are the cause of their families' pain. Yet grief is an important and natural part of loss and it is often better to grieve together than to grieve apart especially after an abnormal and perhaps early death. So legalisation would provide a way to relieve their families of this perceived burden. This raises the important issue of who are the supporters of assisted dying seeking to help? Those who are dying or their families around them?

So the question is, is it right to alter the law to extend the autonomy of some patients if in the process it puts others at risk?

Thirdly I am very concerned about the effect this change will have on the medical profession and the Health Service. If legalized, euthanasia will become a legal way to end suffering; as such it could, paradoxically, be seen as a moral good—and doctors may feel they have to offer it as a "therapeutic" option. This is a dreadful prospect that will utterly demoralize many in the caring professions who are motivated by a desire to support people and enhance life. The impact on our society will be incalculable.

We have evidence of what such practice has lead to elsewhere. In Holland we have seen the extension of application of euthanasia—to those unable to consent as shown in the Remmelink report—that is, very rapidly it became not the consent of the patient that was crucial but the condition of the patient. Later it has been applied even for depression! This point was brought out with force in the very death of the couple suffering from diabetes and epilepsy at the Dignitas clinic in Switzerland in 2003.

My colleagues who work with patients with cancer, both in oncology and palliative medicine are unanimously against this Bill. Some say that there is already widespread practice of ending people's life with morphine or terminal sedation. This is errant nonsense—patients near the end of life need expert care and for that they are given effective pain relief or mild sedatives. They are dying of their disease. There is no doubt that there are difficult and distressing cases. The decisions in these hard cases may not be black and white but various shades of grey. What is immensely helpful at the moment is the absolute clarity that actively ending a patient's life is against the law. Legalisation of euthanasia will lead to even less clarity in our thinking, and ultimately to widespread abuse.

If the Government wishes to do something to relieve the distress of those people who loose hope in the face of a terminal illness, the better way is to provide adequate funding to support and extend the excellent work of those in Palliative Medicine, a discipline founded and developed in the UK of which we should be justly proud. The cardinal purpose of law is surely to protect the vulnerable. Any attempt to legalise euthanasia threatens the most vulnerable in our society and I sincerely hope you will oppose it.

1 September 2004

Letter from Professor Charles F McKhann, MD

1. About Myself

I am a former professor of surgery and vice chair of the Department of Surgery at Yale School of Medicine where I was a specialist in cancer surgery. I have been a specialist in cancer through most of my professional career. I have conducted research and published on the role of the immune system in cancer. More recently I have written about end-of-life care. In particular, I conducted in-depth interviews with people who were dying from a variety of illnesses and with the physicians who cared for them. I published the findings from this research alongside my views on end of life care and physician-assisted death in a book titled "*A Time to Die: The Place for Physician Assistance*" (Yale University Press, 1999). I have also authored another book titled: "*The facts about Cancer: A guide for patients and their families and friends*" (Prentice Hall, 1981).

2. Summary of my Main Points

- Modern medicine exists in a state of optimism that can be hard to deflect. As a result, patients are often given inflated hopes of the possibility that treatment will be successful, in an atmosphere where everything that can be done should be done, unless someone says so.
- This results in many deaths being prolonged and uncomfortable. Almost everyone knows some friend or relative who has had a "bad death".
- In spite of all attempts at comfort (palliative and hospice) care, some patients really do wish to die.
- Terms such as *murder*, *self-murder* (suicide), *killing* and *doctor-executioner* are used deliberately to inflate passions and stifle reason.

— There is so obviously a difference between murder and helping a person die at his own request that gross attempts to blur the distinctions are offensive. They also discourage debate and polarize the community at a time when the public would be better served by thoughtful consideration of all the facets of such a complex issue.

— People who want to die are not necessarily depressed and irrational; rather some have valid reasons that are easily understood by objective and rational people.

— A significant number of physicians who care for the terminally ill have helped their patients to die (in secret).

— Without laws for assisted dying, there can be no control.

— Far from being a step toward moral oblivion, assisted dying may in fact be a step uphill to a better society, which places a greater value on life.

— The passing of compassionate laws will not bring about the end of our civilization any more than with the acts of compassionate physicians

3. Modern Medicine, Technology and Society

Modern medicine exists in a state of optimism that can be hard to deflect. Today, extended life is the gift of public health measures, miraculous drugs, and medical technology. At the same time, the concept that a patient's death is a failure on the part of the physician (alongside the resulting guilt this can induce) is heard throughout medicine.

In such an environment, patients are often given inflated hopes of the possibility that treatment will be successful, in an atmosphere where everything that can be done should be done, unless someone says no. The net result is that many deaths are now prolonged and sometimes very uncomfortable. Almost everyone now knows a friend or relative-who has had a "bad death". Indeed, our ageing population means that many live to experience the accumulation of chronic discomforts and disabilities that are often the price of a long life. Near the other end of the age spectrum, the AIDS epidemic continues to expand, only now the drugs that delay death can result in greater suffering and disability than ever before.

Years ago people feared being snuffed out by disease too early in life. Now, in far greater numbers, they fear lingering deaths that may include years of being incapacitated and in nursing homes. In the United States, many polls show that 65 per cent of the public are now so concerned about how life may end that they feel the law should be changed to permit some access to physician-assisted dying (1).

It is clear that the major goals of medicine are to cure disease, prolong life, and relieve suffering. In the course of many illnesses however, a point is reached where curing the disease and prolonging life are no longer possible. When this happens, the original goal of medicine, to relieve suffering, now becomes the final and only goal for the individual patient. But how far can one go to relieve suffering?

4. Some Patients, Despite Good Comfort Care, Still Want to Die

Comfort (palliative and hospice) care must always be given priority. However, in spite of all attempts at comfort care, some patients really do wish to die. This is usually late in the course of a prolonged, irreversible illness associated with significant suffering.

When a patient wishes to die, two important principles of medical ethics, to benefit the patient and to do no harm, can come into conflict. Helping a person to die can be easily seen as the ultimate harm. On the other hand, what if the patient sees his or her suffering as being a much greater harm than death that is only a few days away? In the patient's eyes, the shorter the period of suffering, the greater the benefit. Most physicians who take care of dying patients have seen situations where death was preferable to continued existence and doing harm was hardly an issue, particularly from the patients' point of view.

5. The Problem with Current Terminology

The terminology associated with physician-assisted dying has acquired its own set of emotional meanings. Terms such as murder, self-murder (suicide), killing and doctor-executioner are used deliberately to inflame passions and stifle reason (2). For example, opponents of physician-assisted dying knowingly use the word killing for its emotional impact. Their intent is to link the common concept of violent killing with the far less threatening concept of assisted dying. Killing implies the willful taking of the life of a person who does not wish to die. The crime of killing (or murder) requires a victim. The basis of our sympathy is that the victim's life is extinguished against his will. But one can hardly speak of a person who is suffering and already dying, and who requests help to speed up the process, as a victim. He may be seen as a victim of his illness, but hardly

of the physician who would help him die. Moreover, his future is not one to envy. Most if not all of the "great good that life had in store" is past.

There is so obviously a difference between murder and helping a person die at his own request that gross attempts to blur the distinctions are offensive. Further, the use of extravagant language discourages debate and polarises the community at a time when the public would be better served by thoughtful consideration of all the facets of such a complex issue.

6. People Can be Rational and Wish to Die

We are gradually recognising that people who want to die are not necessarily depressed and irrational; rather some have valid reasons that are easily understood by objective and rational people.

Competence is a legal concept, but one that often requires medical evaluation. Most physicians feel that they can judge the competence of their patients to make medical decisions, even those involving life and death. The law and the medical profession no longer seriously question the competence of a person who refuses treatment, even when the result would be predictably fatal. In line with this, it should be understood and accepted that the desire of seriously ill patients to shorten the duration of their suffering is by itself no reason to consider them incompetent to make such a medical decision. It can be argued that if by all other criteria a person is competent, but he wishes to die, he is really demonstrating his competence rather than his incompetence in asking that his autonomy be respected.

Closely associated with competence is the question of depression in people who wish to end their lives and suffering early. It is important to note that "Clinical depression", which often leads people to suicide, is usually quite distinct from the sadness and "reactive" depression that is experienced and expressed by people with fatal illnesses (3). Dying patients who may be sad and have "reactive" depression consider their diseases to be a violation of what was previously a normal life. They would prefer to live if they could do so in comfort but would prefer death to their current condition. Most physicians and psychiatrists do not have any trouble distinguishing between these two forms of depression.

7. Physicians and Their Role in Assisted Dying

Polls show that a significant number of physicians who care for the terminally ill have helped their patients to die. More surprising is the finding that moral and religious convictions aside, many more physicians would participate in helping patients die if only the law permitted it. For example, a United States poll showed that 53 per cent of the 938 physicians contacted were in favor of laws that would permit assisted suicide and that 40 per cent would participate if it were legal. The figures for euthanasia were 53 per cent and 33 per cent respectively (4). Another poll showed that 50 per cent of physicians were in favour of assisted suicide and 36 per cent willing to participate (5).

When a patient asks a physician to help him die, the physician may be moved by genuine compassion, recogniszing the severity of suffering and the understandable fear that more and worse may lie ahead. The physician may realise that under similar circumstances he would want the option of escape through death. The physician is the patient's logical choice for help with assistance to die; there is no one else. Not surprisingly, some physicians have a double standard in this respect. They have personal plans or medication for their own use that they are unwilling to extend to their patients.

Any physician who has actively participated in ending a patient's life, such as discontinuing a respirator, realises the heavy weight of responsibility that this entails. This goes beyond our professional responsibilities. Most people swerve vigorously to avoid striking an animal in the road with a car. We share a repugnance for ending life. To be associated with a death is bad enough, to be responsible for it can be unacceptable. But as physicians, if this means relieving the intolerable suffering of our patients, we must occasionally accept moral responsibility for their death.

The American Medical Association holds that approval of assisted dying would tarnish the image of individual physicians who could no longer be considered pure healers and would subsequently damage the image of the profession (5). My own interaction with terminally ill people indicates that both of these suppositions are wrong. During my research with dying patients, when asked if the knowledge that their personal physician had helped others to die would damage their esteem for the individual, they universally said that it would not. Some even said that such knowledge would elevate the physician in their eyes.

8. Current and Future Legal Status

In the United States, assisted dying is against the law in every state except Oregon. However, assisted dying has long been practiced in secrecy as a private matter between patient and physician. Yet without laws there can be no controls. Only through more permissive laws can guidelines be promoted and controls enforced, not to mention the collection of important data, such as who requests assisted dying and for what reasons.

Although I think that legalisation of assisted dying is inevitable, it will be slow to evolve. In the foreseeable future in the United States at least, the goal will be assisted suicide (not euthanasia), by which a physician provides a prescription for a lethal drug which the patient can take at the time of his own choosing or not at all. Many patients take solace in having on hand the means to end their own lives, although they never actually do so. Abuse in the form of coercion is unlikely, and the patient can change his mind up to the last minute. The responsibility for taking the drug, however, is an onerous one for the patient, requiring considerable bravery and determination. The option will be rejected by many and the numbers who see it through will be small.

The Oregon experience is instructive in this regard (6). In 2003, only 67 patients received prescriptions for drugs that could be used to end their lives and 39 died after ingesting medication; 18 died of their diseases without taking the drugs, and ten remained alive at the end of the year. There has been no stampede of unhappy people to end their lives and there is no evidence that any were coerced or that the deaths were medically inappropriate.

9. Concluding Remarks

The twentieth century saw significant changes in our moral and religious views and even greater changes in the acceptance of the traditional precepts by the public. Laws regulating marriage, conception, and maintenance of pregnancy went by the wayside. Attitudes towards sex changed in one generation and attitudes towards sexual preferences are changing almost as rapidly. Our needs for progress and social tolerance are forcing moral and religious attitudes to catch up. Longer lives provide greater opportunities to observe and experience the inevitable slide towards death. As we become increasingly conversant with end of life problems, it will become clear that some people have very valid reasons for not wishing to live any longer.

The process of creating social and legal change, however, begins and ends with the public, and the controversy that surrounds assisted dying has encouraged many people to examine their own wishes more closely. We are in transit from a society that did not want to think about death at all to one that is increasingly concerned about how life may end. Far from being a step toward moral oblivion, assisted dying may in fact be a step uphill to a better society, which places greater value on life. We have no need to be frozen with terror, unable to go up or down, for fear of causing an avalanche that will wipe out all that is good in humankind. The passage of compassionate laws will not bring about the end of our civilization any more than will the acts of compassionate physicians.

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August 2004

Memorandum by the National Centre for Social Research (NatCen)

This evidence is presented by the National Centre for Social Research (NatCen) and is based upon findings from its British Social Attitudes survey.

1. The National Centre for Social Research (NatCen)

1.1 NatCen is the largest independent social research institute in Britain. It designs, carries out and analyses research studies in the fields of social and public policy—including extensive research among members of the public.

2. The British Social Attitudes Survey (BSA)

2.1 The British Social Attitudes survey (BSA) is NatCen's longest running survey. It was set up in 1983 to measure the changing attitudes, values and beliefs of the British public. Over the years it has covered an extensive number of complex social, political and moral issues.

2.2 The sample is designed to yield a representative sample of adults aged 18 and over. It is drawn from the Postcode Address File, a list of addresses compiled by the Post Office. The selection of an adult to interview at each address is carried out randomly.

2.3 The survey is independent of political pressure, an important reason for its success and longevity. It obtains funding from a variety of sources. Core funding is provided by the Gatsby Charitable Foundation, one of the Sainsbury Family Charitable Trusts. A condition of this funding is that all aspects of question design and data analysis are controlled by the survey series' researchers, rather than by the survey's funders. Other funding is obtained from government and grant-giving bodies such as the Economic and Social Research Council.

2.4 The 1995 BSA survey included a set of questions about euthanasia, funded by the Nuffield Foundation. These questions were asked of just under 1,200 respondents, Earlier rounds of the survey had also included some questions about this topic, allowing an assessment of the extent to which attitudes have changed over time. We are currently applying for funds to repeat the 1995 survey, in order to assess whether attitudes have changed over the last decade.

2.5 The remainder of this document describes the key findings of the research to date.

3. Public Attitudes to Euthanasia

3.1 Between 1984 and 1994, the BSA survey found opinion on euthanasia to have shifted in a more "liberal" direction. In both years, respondents were asked "suppose a person has a painful incurable disease. Do you think that doctors should be allowed by law to end the patient's life, if the patient requests it?". In 1984, 75 per cent thought that the law should allow this (24 per cent disagreed), rising to 82 per cent in 1994 (15 per cent disagreed).

3.2 The 1995 survey considered euthanasia in more detail than had previously been possible. It centred upon the acceptability or otherwise of doctors being allowed by law to end a patient's life, reflecting the focus of the debate at that time. It found considerable public support for assisted dying in certain limited circumstances—for example, the case of a person in an irreversible coma on a life-support machine (with their relatives' consent). Nearly nine in 10 (86 per cent) of people thought that euthanasia should "definitely" or "probably" be allowed in these circumstances. (The exact question wording can be found in the appendix to this document, 5.1).

3.3 However, opinion was more divided over cases where the patient was conscious, where the illness was painful but not life-threatening, or where they were simply tired of living. For example, just over half (51 per cent) of people thought euthanasia should be allowed in the case of a person who is completely dependent upon relatives for all their needs but who is not in much pain nor in danger of death. Only 12 per cent felt euthanasia to be acceptable for someone who is "simply tired of living". (The exact question wording can be found in the appendix to this document, 5.2 and 5.3).

3.4 There were marked variations in support for euthanasia between different social groups. The characteristics most strongly associated with a person's views were:

— *Religion:* the non-religious and those who did not attend religious services regularly were notably more pro-euthanasia than their more religious counterparts.

— *Ethnicity:* white respondents were more pro-euthanasia than respondents from minority ethnic groups.

— *Geography:* respondents in England and Wales were more pro-euthanasia than those in Scotland.

— *Disability:* respondents with a disability were more pro-euthanasia than the able-bodied.

— *Educational attainment:* respondents with qualifications were more pro-euthanasia than those with no qualifications at all.

3.5 Once these factors were taken into account, there were no significant differences between different age groups, and between men and women. Although opposition to euthanasia is highest among older groups, this largely reflects the fact that a higher than average proportion of this age group are religious (rather than their age *per se*).

3.6 We also found a clear association between a person's views about euthanasia and their beliefs about a range of "sanctity of life" issues. Being "anti-suicide" or "anti-capital punishment" is strongly associated with being anti-euthanasia.

3.7 The strong relationship between attitudes to euthanasia and religion suggests that euthanasia will become increasingly acceptable as older, more religious, generations gradually die out and are replaced by less religious generations.

4. Contact Details

4.1 This submission was prepared by Alison Park, British Social Attitudes, National Centre for Social Research, 35 Northampton Square, London EC1V 0AX. Telephone: 020 7549 9573. Email: a.park@natcen.ac.uk

5. Appendix—Details of Questions Included in the 1995 Survey

5.1 "Now think about what should happen to someone who has an incurable illness which leaves them unable to make a decision about their own future. For instance, imagine a person in a coma on a life support machine who is never expected to regain consciousness. If their relatives agreed, do you think a doctor should ever be allowed by law to turn the machine off, or not?" (See para. 3.2)

5.2 "And now, how about a person who is not in much pain nor in danger of death, but becomes permanently and completely dependent on relatives for all their needs—for example, someone who cannot feed, wash or go to the toilet by themselves. Do you think that, if they ask for it, a doctor should ever be allowed by law to end their life, or not?" (See para 3.3)

5.3 "Now think of a person who is not ill or close to death but who is simply tired of living and wishes to die—for example someone who is extremely lonely and no longer enjoys life. Do you think that, if they ask for it, a doctor should ever be allowed by law to end their life, or not?" (See para 3.3).

5.4 In all cases, respondents could choose between the following options:

— Definitely should be allowed.

— Probably should be allowed.

— Probably should not be allowed.

— Definitely should not be allowed.

Memorandum by The National Group of Palliative Care Nurse Consultants

1. Collective Statement

The National Group of Nurse Consultants in Palliative Care brings together all the palliative care nurse consultants in England to promote excellence in the field of palliative care nursing. We are a reference group of expert nurses able to comment on and influence the development of policy and advise on its implementation in the field of palliative care.

We firmly believe that the law needs no change to allow for euthanasia or any form of therapeutic killing to meet the needs of people approaching the end of their natural life. It is our view that no suffering is unamenable to relief when a patient and family and expert practitioners work together to tackle its complexities. It is our opinion, based on many years of clinical and personal experience that this Bill is fundamentally flawed and sets a dangerous precedent.

We believe that the participation of nurses in helping patients to die fundamentally undermines the purpose of nursing in its duty of care and erodes trust between nurse and patient. Such a loss of trust could potentially increase suffering.

Nursing is defined by the Royal College of Nursing (2003) as:

> *"The use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems, and to achieve the best quality of life, whatever their disease or disability, until death."*

A key characteristic of nursing is its concern with the whole person and the identification of "human responses to actual or potential health problems" (International Council of Nurses 1987). This means that the public expect a nurse to have the ability and the duty to engage an individual in a relationship of mutual trust, as well as providing for physical comfort. Thus, the relief of suffering, whether physical, social, emotional or spiritual is of central importance to the nurse-patient relationship. The relationship of trust that exists between nurses and the public is based on a dear understanding of the nature and quality of the service provided by nurses.

This brings us to a critical issue in this debate, and that is the motivation and values that nurses have in caring. Our training emphasises care and encourages intuition and emotional intelligence. This is of immense value in walking the path with a patient. However, when the burden of witness is great and a suffering is sustained or the skills to engage and manage it are absent, the natural role that a nurse adopts is to identify with and voice that "pain" rather than to step back and evaluate it. This, however, does not translate into the commonly held myth that 80 per cent of nurses support euthanasia. What it does imply is that 80 per cent of nurses carry emotions accrued from entering into an important, laudable, but unresolved psychological relationship with the dying. Sadly, professional development and supervision only addresses these matters of professional grief and burnout if senior nurses have the skill to recognise and address them. For example, we find repeatedly in the classroom that nurses, regardless of their experience, over the years are deeply uncomfortable with the thought that they may at one time or another have administered an injection that, because it was the last, it must also have been fatal.

Nurses are not good at analytical reasoning because they are not trained to stand back from the burden of witness to reflect on the strategy of care or issues in hand. Rather they will respond to and act upon the raw emotion that flows from the imperative to serve and care, which leads many to consider euthanasia as a necessity because they do not know how to manage suffering.

We now turn to our principle objections.

2. Points of Principle

Unbearable suffering

The Bill states that it will allow:

> *. . . for a competent adult who has suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request; and to make provision for a person suffering from such a condition to receive pain relief medication."*

1. We are gravely concerned as to how the degree of suffering is to be measured. Unbearable is a subjective term, open to interpretation. Patients, families and professionals often have divergent views. Despite a growing body of literature there is no reliable and valid way of measuring degrees of suffering. We re-emphasise that there is no suffering that cannot be relieved or removed if patients have the opportunity for expert clinical support and care by suitably trained staff. We challenge the assumption that the attending physician is able to determine that a level of unbearability has been reached. In our experience suffering is temporal and fluctuates.

2. The Bill's definition of suffering is narrow, somewhat simplified, and in several places is confined to the relief of pain. In contrast there is a growing literature and our clinical experience which point to its complexity. Psychological, spiritual, ontological or existential crises can all come under the rubric of this experience (Dewar and Morse, 1995; George and Martin 2004).

3. We argue that an appropriate response to suffering, which is core to the human experience, is care, commitment and presence. That by being present and accompanying individuals on a difficult journey we can help them explore meaning in their experience. Nurses affirming life dignify the individual. In our experience the number of people for whom this has not been possible, and have persistently asked to be killed is very small[148] and despite their continued suffering they have welcomed and embraced skilled and committed care from both generalist and specialist staff, and most, if not all, changed their mind as their illness progressed.

4. This Bill is a fundamental challenge to values and purpose of nursing. Caring for the dying is core and quintessential to nursing. In the minds of many, suffering is analogous to dying. The notion that one is able to remove suffering from dying is fanciful, and the idea that therapeutic killing further helps this process has

[148] We can quantify this for the Committee at a later date if required.

the potential to drive out nursing from the care of the dying. Other times of human crisis at the end of life where a nursing response is essential will also be irrevocably compromised.

5. Another deep-seated fallacy in the Bill is that the eradication of unbearable suffering through euthanasia will lead to improved care for people who choose this option. According to the Bill a patient need not inform his/her next of kin. We recognise that this takes account of patients' rights to confidentiality, but we are astonished that the Bill's drafters and clinical advisers fail in any measure to register that suffering is both an individual and collective experience. By removing the burden of witness for families and by using euthanasia as a tool to diminish suffering we absolve ourselves from responsibility, devalue human life and dumb down nursing's duty to care for the dying.

6. The Bill makes the assumption that end of life care is physician led. This is an antiquated anachronism.

7. The conscientious objection clause is wholly inadequate and fails to take account for the pivotal role that nurses have in initiating discussions around end of life care.

8. The Bill is incompatible with the principles and practices of Palliative Care, which affirms life and intends neither to hasten nor postpone death (World Health Organisation 2003). This perspective of palliative care has been informed by many years' experience in clinical practice and only recently embraced in national policy.

9. The Bill is incompatible with the current policy direction (the availability of good palliative care for all); we have yet to attain the sentiment of this policy in practice. The intention that palliative care should be a robust alternative to therapeutic killing is laudable but not attainable until tenets of the modernisation agenda (accessibility; equitability, and timeliness) are achieved. We have not achieved these policy objectives by a long way. It would be wrong, therefore to allow this bill to become law.

We now turn our attention to the implications for nursing practice.

3. Points of Practice

The Bill raises four major implications for nursing practice.

3.1 *Qualifying conditions*

From experience we know that the qualifying conditions required by the Bill are extremely difficult to fulfil. In order for a patient to make a request for assisted dying they need to be aware that they are dying. Outside the field of palliative care very few patients are given this information explicitly[149]. A particular need for an improvement in communication skills amongst health care professionals has been identified by the Department of Health and training programmes are currently being rolled out nationally. The knowledge and skills required to discuss the choices available at the end of life, however, lie far in advance of those covered by these training programmes. There are times, even in specialist practice, where we fall short.[150] In short, a workforce who already has major difficulties in discussing simple questions about end of life care (eg preferred place of care) would struggle to include the option of therapeutic killing. We are offended that as a speciality the option of euthanasia might be discussed with dying patients by colleagues who do not have the advanced skills necessary to talk about other end of life issues.

3.2 *Issues of informed consent*

Recent policy developments have reinforced the importance of informed consent. Our professional code of conduct demands that all patients have a right to receive information about their condition in order that they might make informed choices about available care and treatments (Nursing and Midwifery Council 2002). If euthanasia became lawful, nurses caring for the terminally ill would be duty bound to ensure that patients were made aware of assisted dying, *whether they had requested it or not*. The implications of this fact on the nurse-patient relationship are highly significant. If euthanasia were made a "moral good" nurses' ethical responsibility would be turned on its head. The potential for causing psychological, emotional or spiritual distress and suffering to those who do not want to discuss assisted dying is considerable. At a time when individuals are at their most frightened and vulnerable, nurses would be required to discuss death as a "care and treatment" option. As clinical leaders we find this repugnant.

[149] This point can be expanded for the Committee if required.

[150] This point can be expanded for the Committee if required.

3.3 *Implications for the practice of palliative care*

The Bill states that it is a requirement for people seeking assisted death to be seen by a specialist in palliative care. This requirement produces an ambiguous effect. On the one hand it ensures that patients will be made aware of the palliative care expertise available, but on the other hand it marries palliative care with assisted dying. We take issue with the consequences of this ambiguity.

First, the association between assisted dying and palliative care will confuse people's perception of palliative care. The work that has been done to develop an understanding that palliative care is applicable throughout an illness will be undone. The association with death will be re-established. This will be to the detriment of our speciality and the work that has gone in to establishing it at the very time that it is staring to bear fruit. We have to recognise that palliative care is far from the standard and quality it should be.

Second, for any practitioners who are motivated enough to train in palliative care, the internal conflict and discord between the values espoused in the Bill and those in authentic specialist palliative care practice are unsustainable. This discordance undermines inter-team working. The positive model of collaborative and complementary working developed by many palliative care services will be threatened and undermined. In addition we can anticipate that the requirement for a consultation with a palliative care specialist may have a very detrimental effect on Palliative Care Teams with issues of conscientious objection and personal values and views on this issue undermining teamwork and common team values.

Third, the conflicting agendas within the proposed consultation with a palliative care specialist in the Bill will lead to confusion with respect to the intent of the consultation—is it to complete a requirement for the process of attaining assisted dying or to assess how a person's suffering may be supported and if possible relieved through palliative care provision. If it is the former, it is not a palliative care assessment. If it is the latter, then assessment takes at the very least a week, and in proportion of the severity of the suffering, may take months.

The impression we are left with from the Bill is at best lip service and at worst a parody. We are most disappointed that the Lord Joffe and the VES who drafted the Bill clearly have no understanding of the nature, purpose and complexity of authentic palliative care nursing. Assisted dying has no place in palliative care.

3.4 *Preparing Acts*

It is well known in the caring professions that nurses, not doctors are the clinicians who look after patients as they die. There is absolutely no recognition of this in the Bill. If the Bill were to progress to the statute book then nurses would undoubtedly be intimately involved at every stage: sensitive listening and responding to patient's requests by alerting medical colleagues to a request for assisted dying; supporting the patient through the decision making process and acting as the patient's advocate when required; it is also custom and practice that doctors prescribe and nurses prepare and administer medication. This is yet another example of an ill-considered piece of proposed legislation as there is every likelihood that doctors will assume that nurses will also prepare injections for therapeutic killing or administer oral medications for assisted dying. It is nurses who attend to the deceased, support the family through the process and through to bereavement, and not infrequently who are left to field the raw emotions of relatives and friends who may have been unaware of the patient's death.

In Holland the lack of recognition of the breadth and depth of these roles has caused significant confusion over the legal status of the nurse's role in what are called "preparing acts" (Hermsen and Kuunders 2004). There is a tendency to view such acts as technical ones associated with the killing itself. The wider counselling, supporting and comforting roles of the nurse are far more significant. The nurse's role in the provision of and contributing to decision making as equal partners with our medical colleagues must be recognised and legally acknowledged within the framework of the bill. Nurses are personally accountable for their practice, answerable for their actions and omissions, regardless of advice or directions from another professional (Nursing and Midwifery Council 2002). This autonomy must be enshrined within this legislation in order to prevent coercion and erosion of the nurse's integrity. This has been the experience in Holland and will become the experience in the UK.

4. Concluding Comments

We would suggest that what is required to meet the needs of those with unbearable suffering is a collective response on behalf of health and social care providers, policy makers and society in general to close the gaps in service provision and to reduce inequities wherever they exist. These are widespread and wholly unacceptable.

By allowing this Bill to pass an inevitable societal pressure would ensue. As nurses we have a duty to protect the most vulnerable in our society who as a result of such pressure may be made to feel their lives of no value. We believe this can clearly be seen in the Dutch experience where patients who have not volunteered their

consent or sought assisted dying have been killed by doctors against their wishes for economic reasons such as bed pressures (Hendin 2002). The potential for therapeutic killing to be used as an economic health care option in an ageing population and limited economic resources is of the greatest concern.

The legacy that a "bad death" leaves in society is a destructive one and yet evidence exists to demonstrate that skilful nursing care makes a significant difference to patients. Skilled nurses can deliver care in a "friendly" manner that encourages patients to talk intimately about their concerns (Hunt 1992, May 1995). This is particularly important in the cultural context of death and dying. Patients attach importance to such relationships, value them and feel supported by them. Our efforts should be focused on raising the levels of skill amongst the healthcare team to relieve suffering not eliminating the problem by eliminating the patient.

It is consensus view of this expert body of Nurse Consultants in England that if the latter became an option, we would have no choice but to leave nursing.

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3 September 2004

Letter from Professor Richard Glynn Owens

My name is Richard Glynn Owens, I am Professor of Psychology at the University of Auckland, on temporary attachment to the University of Wales. I was previously Professor of Health Studies at the University of Wales (from 1992–95). I am a specialist in the application of psychology to medical problems, and for 20 years have primarily worked in the care of dying people, treating (*pro bono*) dying patients from a number of hospices and hospitals including the Gwynedd Hospice at Home service, the Marie Curie Hospice in Liverpool, the Wigan Hospice, Ysbyty Gwynedd and elsewhere. In New Zealand I was a member of the board of trustees of the South Auckland Hospice. I am the author (with Dr Freda Naylor) of "Living While Dying", a guide for dying patients and those close to them, and recently conducted (with Dr Kay Mitchell) a large-scale study of decisions regarding euthanasia and similar issues in New Zealand and of the practice of euthanasia in New Zealand and the Netherlands. I have a deep commitment to the provision of good palliative care for those patients who are approaching the end of their lives.

In the light of this, I have marked professional concerns regarding the Bill that is proposed to the House. A number of relevant issues will no doubt be brought to the Committee's attention by other commentators, including the observation that some patients who request euthanasia subsequently withdraw those requests if good palliative care is provided, and the commonplace claim in palliative care circles that around 95 per cent to 98 per cent of pain associated with terminal illness can be adequately controlled without recourse to the killing of the patient. Many observers have also raised concerns regarding the so-called "slippery slope", whereby a change which is initially humanitarian may lead to consequences not foreseen or desired by those who made it. Some commentators have also raised concerns regarding the possible impact on doctor-patient relationships that might result from the former being in a position legally to end the patient's life.

Such concerns need to be considered carefully in the preparation of any legislation, and indeed may appear to call into question the need for euthanasia at all. Despite such concerns, however, I am, albeit reluctantly, forced to the conclusion that a change in the law to permit euthanasia under certain circumstances is both necessary and timely. That I come to such a conclusion despite these reservations may seem incongruous, and my reasons for doing so are summarised briefly below:

(i) The common withdrawal of requests; whilst this has been interpreted by some observers to mean that the patient "did not really mean it", this is far from the only interpretation, and indeed it is not surprising that in a context where euthanasia is illegal, a request will be dropped or withdrawn. The only real test of whether the patient "really means it" is to provide the opportunity, together with a provision for revoking the request. This is done in the present Bill.

(ii) The adequacy of pain control; although the figures cited are common within palliative care, there is actually surprisingly little good evidence of their validity. Nevertheless, I remain convinced that a well-conducted study would find that the claims are not far from the truth. In the present context, however, it is important to remember (a) that with the greatest expertise in the world, some forms of pain remain intractable—as with the Cox case many years ago—and (b) that pain is not the only legitimate reason for people wishing to end their lives.

(iii) The "slippery slope"; whilst much vaunted, this concept has neither been critically examined nor rigorously investigated. Although it is true that sometimes one change is subsequently followed by further changes in the same direction (for example the Clean Air Act of the 1950s being followed by other changes designed to enhance protection of the environment, like the removal of lead from petrol) these need to be considered in the context of the underlying processes. Often the shifts mark independent consequences of broader societal change, and of course in some instances they result from discovery that what seemed like a daunting prospect when making even a small change turned out to be less problematic than originally expected, leaving people confident to make others. There is no reason whatever to believe, as some are wont to claim, that provision of voluntary euthanasia would lead to people's lives eventually being ended against their will; indeed if such were to happen, one might more have expected that to be a consequence of a slippery slope from the days of capital punishment, with the slope taking us from one group being killed against their will to others. All too often the notion of a "slippery slope" is invoked without a logical basis or detailed analysis simply to shore up an otherwise inadequate argument.

(iv) The impact on doctor-patient relationships; although this has been raised by a number of observers, it does not appear to correspond with the evidence, nor to provide any kind of insuperable obstacle. Indeed, since we are talking of doctors acceding to patients' wishes, it is arguable that such a change would enhance rather than impair relationships. Moreover, if this were seen as a major objection, there is no real obstacle (as I note below) to moving the task away from the medical profession.

It is perfectly clear that being at the end stages of one's life does not in itself preclude one from making clear, reasoned choices that are the consequence of thinking logically. From a purely civil libertarian perspective one would need especially compelling arguments to continue restricting the options available to needy individuals who are in the best position to determine their own preferences and values. I do not believe that the arguments commonly presented provide justification for such restriction, and therefore somewhat reluctantly support the passing of a Bill such as is presently proposed.

In the light of these considerations, I believe that a Bill such as the one that has been drafted needs to be passed into law. I should remark, however, that there are matters of detail which the Select Committee may wish to consider further. Primary amongst these are;

(i) The Bill correctly alludes to the need to ensure that a patient is competent, but fails to address the requirements for expertise in those involved. Whilst it is likely that a psychiatrist may have some experience and knowledge of normal psychological processes, I would be disinclined to expect substantial expertise in this field below Consultant level. I would therefore, given the importance of the issue, suggest that the Committee consider requiring that any referral be required to be dealt with specifically by a Consultant, rather than simply a "psychiatrist". It should be remembered, however, that the key expertise in assessing cognitive processes lies not with psychiatry, which is concerned with mental disorders, but with psychology, which is concerned with the broad field of cognitive functioning. I would therefore suggest that the Bill provide for the option that the assessment of competence be made either by a Consultant Psychiatrist or a Consultant Clinical Psychologist. This would also have the additional benefit of increasing the number of available professionals. The notion that a solicitor has special expertise in this field seems incongruous, although of course it would be a necessary part of any solicitor's Code of Practice to draw attention to any evidence for incompetence.

(ii) It is assumed throughout the Bill that the ending of the patient's life shall be performed by a medical practitioner. There seems no reason in principle for such a restriction, and evidence from our own research suggests that this may not be essential, and that (for example) a nurse with appropriate expertise may be equally competent. I would suggest therefore that the Committee give consideration to changing the wording to suggest that the act be performed "under medical supervision", giving

backup in the case of complications but not limiting the actual administration of the procedure to the medical profession. This of course may also go some way towards alleviating the concerns of those who worry about a possible impact on doctor-patient relationships.

(iii) Our own research into the provision of euthanasia by doctors in Holland (the only research of its kind, to date) has highlighted the extent to which such doctors find the procedures distressing. There is a very real risk that the provision of euthanasia will have a stressful impact on practitioners. I would suggest therefore that the Committee consider incorporating into the Bill a requirement that provision be made for counselling or other support for those who perform euthanasia.

I have deliberately limited my comments on these issues to brief remarks, in the light of the undoubted wealth of submission that will be made regarding this proposal. I should emphasise, however, that I am entirely willing to attend the deliberations of the Committee if required to expand on these or other matters.

Memorandum by the All-Party Parliamentary Pro-Life Group

SUMMARY

1. The All-Party Parliamentary Pro-life Group upholds the sanctity of human life from conception until natural death. Every human being, regardless of disability or physical or mental health, possesses a fundamental worth and dignity for as long as he or she is alive. Recognition of the fundamental worth and dignity of every human being is the indispensable foundation of justice in society.

2. The prohibition against intentional killing is fundamental to our whole legal system. The 1993–94 House of Lords Select Committee on Medical Ethics declared that this prohibition is "*the cornerstone of law and of social relationships.*" (Para 237)

3. The Assisted Dying for the Terminally Ill Bill ("the Bill") would fatally undermine the prohibition. Allowing doctors to help their patients to die corrupts the doctor-patient relationship.

4. Rules in our moral and legal codes against actively causing the death of another person are not isolated fragments. They are threads in a fabric of rules that support respect for human life. The more threads we remove, the weaker the fabric becomes.

5. We do not propose to look in any detail at the substance of the Bill. Tinkering with a Bill which seeks to legalise euthanasia and assisted suicide will not spare society from its disastrous consequences.

6. We propose to focus on three particular issues; the conclusions of the House of Lords Select Committee on Medical Ethics, ethical arguments against intentional killing of the type envisaged by the Bill and practical arguments against the Bill.

THE CONCLUSIONS OF THE HOUSE OF LORDS SELECT COMMITTEE ON MEDICAL ETHICS

7. After extensive consideration the Committee's Report unanimously recommended amongst others that: *There should be no change in law to permit euthanasia."* (Para 278); "*We recommend no change in law on assisted suicide.*" (Para 295)

8. The conclusions of the Select Committee on Medical Ethics are as pertinent now as they were nine years ago. We ignore them at our peril. We fail to see what has happened in society in the intervening decade that would lead your Select Committee to endorse the Bill and thereby disagree with your predecessor's unanimous conclusion. In particular, palliative care and the management of pain have improved. "*The Law in its present form needs no change for comprehensive and effective management of distress and agitation, including high doses of analgesia and sedation, at any stage of disease, which is safe and effective if given by personnel properly trained in Specialist Palliative Care. To infer otherwise is misleading and mischievous.*"[151]

9. Since 1994 there have been a number of high profile cases that have sought to advance the argument for euthanasia and assisted suicide. One cannot fail to be moved by the tragic cases of individuals like Diane Pretty and Reginald Crew. We recognise the suffering of patients with Motor Neurone Disease and similarly debilitating diseases and acknowledge the anguish of the families who care for loved ones with these conditions.

10. However, it is worth recalling the conclusions of the Select Committee on Medical Ethics: "*individual cases cannot reasonably establish the foundation of a policy (the legalisation of euthanasia) which would have such serious and widespread repercussions . . . the issue of euthanasia is one in which the interest of the individual cannot be separated from the interest of society as a whole.*" (Para 237)

[151] The Patient (Assisted Dying) Bill: A joint briefing paper by the Association for Palliative Medicine and the National Council for Hospice and Specialist Palliative Care Services—May 2003. Presented in the House of Lords on 3 June 2003.

11. As parliamentarians we recognise, as no doubt you do, that we have a duty to legislate for society as a whole, not for individual cases. Experience with abortion legislation has taught us that no matter how well-intentioned proponents of legislation may be, where the legalisation of intentional killing is concerned it is impossible to introduce adequate safeguards against abuse.

Ethical Arguments Against the Assisted Dying for the Terminally Ill Bill

12. The Select Committee on Medical Ethics correctly noted that the prohibition on intentional killing "*protects each one of us impartially, embodying the belief that all are equal.*" (Para 237). They had no wish to see that protection diminished.

13. There is wholeness to our human nature, not a dualistic account of a biological life and a biographical life with the latter taking precedence over the former. Human beings share equally an intrinsic dignity and value by virtue of our shared humanity.

14. Consequently, "*[I]n sustaining human bodily life, in however impaired a condition, one is sustaining the person whose life it is. In refusing to choose to violate it, one respects the person in the most fundamental and indispensable way*".[152]

15. It is in this context that the Select Committee on Medical Ethics referred to the prohibition on the killing of innocent human beings as providing the cornerstone of whatever rights an individual may have.

16. Nowadays we hear so much talk of autonomy, the right to do with one's life as one chooses. Autonomy is one of the buzzwords of the pro-euthanasia lobby. Properly understood the concept of autonomy, in particular the right to refuse medical treatment, is designed not to give persons a right to decide whether to live or die but to protect them from the unwanted interferences of others. The concept is rooted in the notion of the intrinsic value and dignity of the human person and thus can be overridden when autonomy is exercised in ways which contravene this notion or place other members of society at risk of harm.

17. A proper understanding of autonomy should lead you to reject Lord Joffe's Bill. The Bill has the potential to compromise the autonomy of some of the most vulnerable members of society, not least the terminally ill, the disabled and the elderly.

18. One must also consider the autonomy of members of the medical profession. The Joint Committee on Human Rights has declared the conscience clause in the Bill[153] to be contrary to the European Convention on Human Rights under Article 9(1), respect for the individual's right to freedom of thought, conscience and religion.

19. It is a sad fact that there are now very few gynaecologists practising in the United Kingdom who are opposed to abortion. Abortion is such a standard gynaecological practice that it is nigh impossible to specialise in that field and refuse to carry out abortions. Doctors opposed to abortion have been forced to specialise in other areas where no such ethical conflict arises.

20. If euthanasia and assisted suicide were legalised we would witness a similar phenomenon in geriatric care, in palliative care and in the hospice movement—regardless of whether the legislation contained a conscience clause. Doctors opposed to these practices would gradually be squeezed out.

Practical Arguments Against the Assisted Dying for the Terminally Ill Bill

21. We believe that it is no coincidence that the organisations representing those who would be affected most by the Bill—the elderly, the terminally ill, the disabled and the medical profession—are opposed to any change in the law to allow euthanasia and assisted suicide.

22. The Disability Rights Commission does not support the legalisation of voluntary euthanasia and assisted suicide. It argues that *"in the current climate of discrimination against disabled people, where a lack of access to palliative care and social support means that free choice does not really exist, the threat to the lives of disabled people posed by such legislation is real and significant."*[154]

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[152] Finnis, J M, "A philosophical case against euthanasia" in Keown, J, (ed) *Euthanasia Examined—Ethical, clinical and legal perspectives* (Cambridge: Cambridge University Press, 1995) p 32.

[153] Clause 7 of the Assisted Dying for the Terminally Ill Bill.

[154] Disability Rights Commission policy statement on voluntary euthanasia and assisted suicide; http://www.drc-gb.org/uploaded_files/documents/10_444_181203_Euthanasia.doc.

23. The British Medical Association is also opposed. "*The BMA has consistently opposed euthanasia and physician assisted suicide . . . we believe that in the case of euthanasia and assisted suicide, benefit for an individual in terms of having their wishes respected, is only achievable at too high a cost in terms of potential harm to society at large.*"[155]

24. Beverley Malone, General Secretary of the Royal College of Nursing has declared that "*The RCN believes that the practice of euthanasia is contrary to the public interest, to nursing and medical ethical principles as well as patients' civil rights. The RCN is opposed to the introduction of any legislation which would place responsibility on nurses and other medical staff to respond to a demand for termination of life from any patient . . .*".[156]

25. Bodies representing those working within the Hospice Movement and the palliative care sector argue that euthanasia, once accepted, "*is uncontrollable for philosophical, logical and practical reasons rather than slippery slopes of moral laxity or idleness. Patients will almost certainly die without and against their wishes if such legislation is introduced.*"[157]

26. The most recent independent UK survey of doctors' opinions on this matter[158] revealed that almost three out of four doctors (74 per cent) would refuse to perform assisted suicide if it were legalised. A clear majority (56 per cent) also considered that it would be impossible to set safe bounds to euthanasia. To the question "As a doctor do you agree with assisted suicide?" 25 per cent agreed, 60 per cent disagreed and 13 per cent were undecided. The number who rejected euthanasia was higher—61 per cent as compared with 22 per cent in favour and 14 per cent undecided. Not one palliative care doctor who responded to the survey would practice either euthanasia or assisted suicide while 66 per cent of doctors considered that the pressure for euthanasia would be lessened if there were more resources for the hospice movement.

27. In the face of such overwhelming opposition from those who would be affected most by the Bill it is impossible to envisage how it could be practically implemented.

28. One must also consider what has happened in those jurisdictions where euthanasia and/or assisted suicide has been legalised.

29. In Oregon, where assisted suicide was legalised in October 1997, more than a third of the patients in one study requested assistance in suicide because they perceived themselves as a burden to others.[159] Thankfully, only three of these patients received prescriptions for lethal medications which suggests that physicians were reluctant to accede to patients' requests for assistance with suicide.

30. Furthermore, there is little evidence of any improvement in palliative care services in Oregon. According to a recently published study by Oregon Health and Science University,[160] half of the family members of dying patients surveyed between 2002 and 2002 said their loved ones' pain was moderate or severe in the week before they died. Prior to 1997 when assisted suicide was legalised in Oregon, only one-third of family members surveyed rated the pain as moderate or severe.

31. The latest empirical evidence from the Netherlands contained in the official report by Van der Wal and Van der Maas[161] notes that the frequency of ending of life without the patient's explicit request has shown no decline over the years studied, 1990, 1995 and 2001. In 2001, the most recent year for statistics are available, 900 out of 3,800 cases of euthanasia or assisted suicide (approximately one-quarter) *were without the patient's explicit request.*

32. The latest official report on euthanasia in the Netherlands[162] also shows that only 54 per cent of cases of euthanasia were reported to the regulatory authority and "life terminating treatment without explicit request of the patient is still seldom reported (less than one per cent)." According to a press reports, the low notification rate is because doctors wished to avoid the "*administrative hassle*" of reporting a euthanasia case and were concerned they might have breached the regulations.[163]

[155] BMA Briefing on the Assisted Dying for the Terminally Ill Bill: http://wvvw.bma.org.ulc/ap.nsf/Content/Assisteddying.

[156] Hemmings, P, "Dying Wishes" *Nursing Times* 25 November 2003, Vol 99, No 47, p 20.

[157] The Patient (Assisted Dying) Bill: A joint briefing paper by the Association for Palliative Medicine and the National Council for Hospice and Specialist Palliative Care Services—May 2003. Presented in the House of Lords on 3 June 2003.

[158] Survey on Euthanasia and Assisted Suicide Prepared for "Right to Life" lobby group. Results from 986 interviews 26 March–9 April 2003. Opinion Research Business, 9-13 Cursitor Street, London, EC4A ILL; www.opinion.co.uk.

[159] Ganzini *et al*, "Physicians" Experiences with the Oregon Death with Dignity Act', *New England Journal of Medicine*, Vol 342, 2000, No 8, p 557.

[160] Nowak, P, "Palliative Care for Elderly, Disabled, Worse Since Assisted Suicide Legalised", http://www.lifenews.com/bio406.html.

[161] Van der Wal and P Van der Maas, Chapter 19 of their report on euthanasia, 2003. *See* also Dr Bregje D Onwuteaka-Phillipsen *et al*, "Euthanasia and other end of life decisions in the Netherlands in 1990, 1995 and 2001", *The Lancet*, 17 June 2003: http://image.thelancet.com/extras/03art3297web.pdf.

[162] *Ibid.*

[163] Report from the Expatica news website on 23 May 2003; www.expatica.com.

33. In a study published in the New England Journal of Medicine in 2000 it was reported that one of the problems most frequently reported with the performance of euthanasia and physician assisted suicide in the Netherlands is a "*longer than expected interval between the administration of the lethal drug . . . and the patient's death.*"[164]

34. The following excerpt from this study gives a chilling glimpse into the practical difficulties with euthanasia and physician assisted suicide: "*In most of these cases, the patient did not die as soon as expected or awoke from coma, and the physician felt compelled to administer a lethal injection because of the anticipated failure of the assisted suicide. In some cases, the physician administered a lethal injection because the patient had difficulty swallowing the oral medication, vomited after swallowing it, or became unconscious before swallowing all of it.*" *So much for death with dignity.*

35. Empirical evidence from the Netherlands reinforces the argument that it is impossible to set safe bounds to euthanasia so as to ensure that only those who have expressed a persistent, voluntary and well-considered request are put to death. The Dutch experience contradicts the claim that legalisation "brings euthanasia out of the closet" and subjects it to regulation. It simply produces more euthanasia, not more control.

36. Those in favour of the Bill often allege that euthanasia and physician assisted suicide are a widely known fact of medical life, but are usually carried out at the doctor's discretion or in secrecy—hence the need for legislation and proper regulation. Notwithstanding the Dutch experience where legalisation has failed to introduce greater regulation, these allegations are rarely substantiated. They are a slur on the medical profession and should not be allowed to pass unchallenged.

37. The most recent survey of medical opinion cited earlier[165] explodes the idea that people are clamouring for euthanasia. In response to a question asking how many patients had requested euthanasia during the past three years nearly half (48 per cent) of the doctors said not one; 37 per cent quoted less than five; 11 per cent gave numbers between five and 10 patients; only two per cent gave figures of more than 10. In their comments doctors said that in their experience requests for euthanasia were often "*cries for help that have been resolved with good symptom control . . . they almost invariably want relief from distress*".

38. The number of requests for euthanasia from relatives was even lower than from patients themselves. 68 per cent of doctors said that none had approached them in the last three years; 22 per cent quoted less than five such experiences; five per cent quoted figures between five and 10 and one per cent gave numbers of more than 10. Three per cent said they did not know or that the question was not applicable to them.

39. Proponents of euthanasia and assisted suicide also conflate these practices with perfectly legitimate end of life care. Doctors are regularly called upon to decide to withhold or withdraw life-sustaining treatment in the knowledge that death will result. However, knowledge that a certain course of conduct may bring about death does not automatically constitute euthanasia. Intention or purpose is the key. If treatment is withheld or withdrawn with the purpose of bringing about death this constitutes euthanasia and is unethical. However, it is perfectly legitimate to withhold or withdraw medical treatment when it is considered that the burdens of such treatment outweigh the benefits, or where the patient is dying and the treatment would be regarded as unduly intrusive and inappropriate or where the risks of such treatment would be excessive.

Conclusion

40. We urge your Committee to reject in its entirety the Assisted Dying for the Terminally Ill Bill.

41. The Bill would irrevocably and fatally damage the practice of medicine in the United Kingdom. The most vulnerable members in our society, the elderly, the terminally ill and the disabled would be at greatest risk of premature death if this Bill were implemented.

42. When there is a pressing need to tackle the under-funding and regional disparities in palliative care for the terminally ill and personal care packages for the elderly and those with disabilities it is regrettable that parliamentary time is being taken up with "assisted dying" legislation. Of far greater use to the elderly, terminally ill and those with disabilities would be some form of "assisted living" legislation.

43. We would be happy to appear before your Committee to give oral evidence.

Jim Dobbin MP
Chairman, All-Party Parliamentary Pro-life Group

[164] Groenewoud *et al*, "Clinical Problems With The Performance Of Euthanasia And Physician-Assisted Suicide In The Netherlands", *New England Journal of Medicine*, Vol 342, 2000, No 8, p 551.

[164] Survey on Euthanasia and Assisted Suicide Prepared for "Right to Life" lobby group. Results from 986 interviews 26 March–9 April 2003. Opinion Research Business, 9–13 Cursitor Street, London, EC4A 1LL; www.opinion.co.uk.

Ann Winterton MP, Lord Stallard, Baroness Masham of Ilton, Claire Curtis-Thomas MP, Rt Hon Ann Widdecombe MP
Vice-Chairmen, All-Party Parliamentary Pro-life Group

Joe Benton MP, Kerry Pollard MP
Honorary Secretaries, All-Party Parliamentary Pro-life Group

Rev Martin Smyth MP, Andrew Selous MP
Honorary Treasurers, All-Party Parliamentary Pro-life Group

August 2004

Letter from Dr Louise Gibbs, Dr Emma Hall, Dr Victor Pace, Dr Debra Swann and Dr Nigel Sykes, Consultants in Palliative Medicine, St Christopher's Hospice, London

We write in support of the submission to the Select Committee from the Association of Palliative Medicine, of which we are all members. As consultants in palliative medicine we jointly care for over 1,800 terminally ill people each year either in their own homes or in the Hospice wards. In our view the Association has produced an excellent summary of the key issues that relate to the Bill's provisions and we fully endorse its clear opposition to the legalisation of physician assisted suicide or euthanasia. Among the submission's many well-taken points we would like to emphasise the following:

— Legalisation of euthanasia/assisted suicide is likely to jeopardise the vulnerable. As the submission explains this is partly because of the sense of burden many terminally ill people feel, that may impel them to offer themselves for euthanasia, once available, as the "decent thing" to do for the sake of their families. It is also because once precipitating death has been declared a moral good by being legalised in certain circumstances those circumstances will inevitably, through a process of attitudinal shift, be widened to include others, particularly the incompetent. Involuntary euthanasia will speedily become a reality and euthanasia will become the alternative to good care for an increasing range of conditions. Additionally, should a request for euthanasia become a ticket to a palliative care bed this will distort clinical priorities and potentially deny needy people the care they deserve.

— While approving of the inclusion in the draft Bill of a conscience clause for doctors who feel unable to take part in assisted suicide/euthanasia, we deprecate the legal requirement for such doctors to refer such patients to another doctor without similar scruples. This amounts to forced complicity in the euthanasia/assisted suicide process and would be an unjust and intolerable imposition upon the doctors concerned.

12 August 2004

Memorandum by Ms Karen Sanders

I am the elected Chair of the Royal College of Nursing Ethics Forum Steering Committee and a member of the Royal College of Nursing Ethics Advisory Panel; however I am submitting the following paper in a personal capacity.

I have been a registered nurse in the UK for 21 years. I continue to practice clinically as an agency nurse. My area of clinical expertise is Intensive Care and Neurosciences nursing, which I teach along with Healthcare Ethics at the London South Bank University, London. I have previously been called to give evidence to the Council of Europe and have lectured extensively on this subject.

I would like to confirm that I have been a member of the RCN for 10 years and in this time I have never publicly criticised a formal RCN Parliamentary submission. As this is a conscience issue and because I believe the submissions received during the RCN's formal consultation process were overwhelmingly in favour of changing the law, it is with a heavy heart that I write expressing a contrary view to the RCN's submission.

In the interests of nursing and their patients, I feel that it would be helpful to provide some background information on why the majority of UK nurses support a change in the law.

The arguments are as follows:

1. UK nurses support a change in the Law.
2. Nurses in the UK and abroad already help their patients to die.
3. The current law makes matters worse not better.
4. Legislation would help the nurse and help the patient alike.

5. Palliative care does not negate requests for assistance to die.
6. Assisted dying legislation can help to improve end of life care.
7. End of life treatment options are ethically complex and not necessarily better or worse than assisted dying.

Background

The Assisted dying for the Terminally Ill Bill has been developed to enable a competent terminally ill patient who is in unbearable suffering, the right to request assistance to die. In order to have their request accepted, the patient must meet stringent requirements and safeguards. Should their request be accepted, be given help to die via the doctor prescribing medication that the patient self-administers. If however the patient is unable to self-administer medication (as would have been the case for Diane Pretty), the doctor is allowed to do this for them.

The Bill also allows for terminally ill patients to request and receive as much pain relief as they feel necessary. This is an important aspect of the Bill because currently doctors and nurses can be fearful of providing adequate pain relief due to concerns about drug tolerance, addiction or fear of shortening the patient's life.[166]

The remainder of this submission outlines key reasons why the law needs to be changed.

1. UK Nurses Support a Change in the Law

Nurses are the healthcare professionals who spend most time with patients. We are the ones who day in and day out, witness the severe and intolerable distress that can accompany patients who are dying. Indeed for many patients, it is not death they fear, but the disintegrating and often dehumanising process of dying. It is perhaps safe to say that due to the time nurses spend with patients they may feel most able to open up to us about their fears and their needs at the end of life. In the Netherlands, patients often first approach nurses about their desire for an assisted death.[167]

It is therefore very important to take serious note of the fact that in a recent Nursing Times Survey, one in two nurses did not think it was unethical to administer a lethal injection at a patient's request. Even more importantly, two thirds of nurses supported a law on medically assisted dying. 83 per cent of such nurses viewed this should be for terminally ill patients. 31 per cent believed they should be allowed to assist patients to die.[168]

It is interesting to note that in Oregon, a US state that has assisted dying legislation, 59 per cent of hospice nurses and social workers working are supportive of the law. A further 17 per cent remain neutral.[169]

2. Nurses in the UK and Abroad Already Help Their Patients to Die

In the aforementioned *Nursing Times* Survey, one in four nurses had been asked by patients to help them die. Forty-four per cent admitted to having administered prescribed interventions that may have contributed to a patient's death. Even when taking into account the principle of "double effect" (which itself is ethically complex and unclear), we can safely assume that on at least some occasions, the intention of these actions would have been to actively bring about death. Elsewhere, research has found that despite it being prohibited, nurses do help their patients to die:

— Asch (1996)[170] reported that 17 per cent of critical care nurses surveyed had received patient or family requests to die. Sixteen per cent had helped patients to die.

— Leiser *et al* (1998)[171] reported on nurses working in HIV/AIDS. Thirty-seven per cent had received a request to die and 15 per cent had helped a patient to die.

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[166] McNair, H 1999. "Let's Put an End to Pain", *Nursing Times* 95(6): 36–37 and Solomon, M, O'Donnell, L, Jennings, B, Guilfoy, V, Wolf, SM, Nolan, K, Jackson, R, Koch-Weser, D, and Donnelley, S, "Decisions near the end of life: professional views on life-sustaining treatments", *American Journal of Public Health* 1993; 83: 14–22.

[167] van de Scheur, A and van der Arend, A, "The role of nurses in euthanasia : a Dutch study", *Nursing Ethics* 1998; 5 (6): 497–508.

[168] Hemmings, P, "Dying Wishes", *Nursing Times* 2003; 99 (47): 20–23.

[169] Ganzini, L, Harvath, TA, Jackson, Goy, ER, Miller, LL, and Delorit, MA, "Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide", *NEJM* 2002(b); 347: 582–88.

[170] Asch, DA, "The role of critical care nurses in euthanasia and assisted suicide", *New England Journal of Medicine* 1996; **334 (21)**: 1374–1379.

[171] Leiser, RJ, Mitchell, TF, Hahn, J, Slome, L, Abrams, DI, "Nurses attitudes and beliefs toward assisted suicide in AIDS", *J Assoc Nurses AIDS Care* 1998; **9**: 26–33.

— Ferrell *et al* (2000)[172] found that over 20 per cent of oncology nurses had received a patient request to die. Three per cent had helped a patient receive a lethal prescription and 3 per cent had actually administered a lethal injection.

— Volker (2001),[173] Magnusson (2002)[174] and Schwarz (2004)[175] have all, via a more qualitative approach, found nurses to both receive requests for assistance to die and actively help their patients to achieve this.

3. The Current Law Makes Matters Worse Not Better

Due to assisted dying being prohibited, nurses who are faced with patient requests to die have no ethical codes of practice or protocols (such as those in the Bill) to help guide nurses in responding to such requests. There are also other far-reaching concerns that result from prohibition of this practice. These include:

1. Nurses who actually help terminally ill patients to die, do so with no guidelines, safeguards or support.
2. Nurses who do help patients to die are open to prosecution.
3. Without legislation and resulting safeguards, vulnerable patients are at risk from abuse. This can perhaps best be highlighted by studies that have found rates of non-voluntary assisted deaths to be higher in countries that have no assisted dying legislation (eg Australia[176] and Belgium[177] before legislation) than in the Netherlands.[178] Academics have cited high rates of non-voluntary assisted dying as a core reason for Belgium's 2002 assisted dying legislation.[179]
4. Patients may be assisted to die when alternatives such as palliative care or pain relief, may have met their needs. This concern has been highlighted by Magnusson's (2002) research. He observed that:

   "*Prohibition drives assisted death underground. At present, healthcare workers who perform euthanasia determine the conditions for their own involvement. Secret euthanasia, without appropriate regulation, raises many disturbing issues.*"[180]

   These disturbing issues include botched attempts (20 per cent of cases Magnusson studied), patients being ambivalent about going through with the process, and/or being given assistance to die when patients are not near the end of their life.
5. Due to assisted dying being prohibited, patients may be driven to seek assistance to die from their loved ones. This can have disastrous consequences (eg see Sanderson, 2002).[181] Some patients may even go abroad to places like Dignitas in Switzerland to die. Dignitas do not appear to have any clear safeguards and as a result, can help patients to die that would not meet the requirements set up in the proposed UK Bill.

Legislation that incorporates strict safeguards as found in the Assisted Dying for the Terminally Ill Bill, is the only way to ensure these highly concerning issues do not continue to occur.

4. Legislation Would Help the Nurse and Help Patient Alike

A transparent legal system with regards to assisted dying would ensure a far safer process than is currently in place. Despite this fact, those opposed to assisted dying cite fears that legislation would destroy patient and healthcare professional communication and trust. All evidence actually shows the opposite to be the case. For example, surveys find that in Europe, the Dutch respect and trust their doctors most![182] Further, a recent in-depth European wide study supports the fact that openness and transparency of practice within end of life care

[172] Ferrell, B, Virani, R, Grant, M, Coyne, P and Uman, G "Beyond the Supreme Court decision: nursing perspectives on end-of-life care", *Oncol Nurs Forum* 2000; **27**: 445–555.

[173] Volker DL. "Perspectives on assisted dying: oncology nurses' experiences with requests for assisted dying from terminally ill patients with cancer", *Oncol Nurs Forum* 2001; **28**: 39–49.

[174] Magnusson, RS, *Angels of death: Exploring the euthanasia underground* (Yale University Press, 2002).

[175] Schwarz, JK, "Responding to persistent requests for assistance in dying: a phenomenological inquiry", *International Journal of Palliative Nursing* 2004; **10 (5)**: 225–236.

[176] Kuhse, H, Singer P, Baume P, *et al.* "End-of-life decisions in Australian medical practice", *MJA* 1997; **166**: 191–197.

[177] Deliens, L, Mortier, F, Bilson, J, *et al,* "End-of-life decisions in medical practice in Flanders, Belgium: A nationwide survey", *The Lancet* 2000; **356**: 1806–1811.

[178] Onwuteaka-Philipsen, BD, van der Heide, A, Koper, D *et al,* "Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995 and 2001", *The Lancet* 2003; **362**: 395–399.

[179] Deliens L and Bernheim JL. "Palliative care and euthanasia in countries with a law on euthanasia". *Palliat Med* 2003: **17(5)**; 393–4.

[180] Magnusson 2002 *ibid.*

[181] Sanderson, M, *A memoir: Wrong Rooms* (Scribner: London, 2002).

[182] Kmietovicz, Z, "R.E.S.P.E.C.T—why doctors are still getting enough of it", *BMJ* 2002; **324 (7328)**: 11–14.

enables better communication between healthcare professionals and their patients. When compared to doctors in other countries, doctors in the Netherlands (followed by Belgium and Switzerland where assisted dying is allowed) consistently communicated more with patients and their families about end of life medical decisions.[183] Doctors in Denmark, Sweden and Italy—countries that are essentially closed to open discussion about, and practice of, assisted dying—consistently communicated with dying patients and their families *least*.

Belgium is the only country to include nurses within their assisted dying legislation. It is interesting to note that in this European study, Belgian doctors communicated with nurses about end of life decisions more often than doctors in any other country (this was followed by the Netherlands and then Switzerland).

The current lack of guidelines for nurses on how to deal with requests from patients to die combined with the fact assisted dying is prohibited, serves to prevent nurses from openly communicating and exploring the needs and fears of dying patients. This is problematic, particularly when considering evidence from Oregon. Work undertaken in Oregon has highlighted that when terminally ill patients ask about receiving assistance to die, the healthcare professional openly explores the reasons behind their request. This usually results in the patient's needs being met in other ways.[184] Thus, regardless of whether a patient actually received assistance to die, patients being able to openly communicate with healthcare professionals about their needs and fears at the end of life may actually be the most important aspect of legislation. Ann Harvath, a nurse and Associate Professor and Co-Director of the Best Practice Initiative at Oregon Health Science University, exemplifies this point. With regards to Oregon assisted dying legislation (the ODDA), she comments:

> "*One of the benefits that I believe has come with the ODDA is that a number of hospice nurses report it provides them with an opportunity to discuss the patient's fears related to death. Nurses get so many questions from patients about using a lethal prescription who have no serious interest in taking a lethal prescription. It opens conversations to such questions as 'what are you afraid of'? Before assisted suicide, patients' fears didn't always surface so readily.*"[185]

5. Palliative Care Does Not Negate Requests for Assistance to Die

Many professional organisations such as Macmillan[186] and the National Hospice Council[187] recognise that palliative care cannot meet the needs of all patients. In this way, even if the best available palliative care was in place across the whole of the UK, some patients will still want assistance to die. This is particularly as reasons terminally ill patients seek assistance to die are multiple and complex and cannot be simplified into singular "treatable" issues such as "pain" or "depression". For example, issues concerning loss of control, dignity and being less able to engage in activities making life enjoyable are the most commonly cited reasons for Oregonians who receive assistance to die.[188]

Ganzini and Back (2003)[189] recently wrote an article for Palliative Medicine outlining the experience of Oregon. In this article they clarified that Oregonians who receive assistance to die are not depressed. They further commented how research has identified that there seems to be a certain "type" of person who receives assistance to die whereby:

> "*The value they place on control and independence appears lifelong . . . When exposed to the exigencies of the dying process, they face dreaded dependency and loss of control not easily addressed by advanced directives and symptom management. Responding with more palliative care is a double edged-sword: Although data from Oregon support that palliative interventions can lead some patients to change their mind about assisted suicide, for other patients more care fuels fears of more dependence on others.*"

[183] van der Heide, Agnes; Deliens, Luc; Faisst, Karin; Nilstun, Tore; Norup, Michael; Paci, Eugenio; van der Wal, Gerrit; van der Maas, Paul J, "End-of-life decision-making in six European countries: descriptive study", *The Lancet* 2003; **362**: 345–350.

[184] Bascom, PB and Tolle, SW, "Responding to requests for physician assisted suicide: 'These are uncharted waters for both of us . . .'", *JAMA* 2002; **288 (1)**: 91–98.

[185] Sadowsky interviewing Ann Harvath: Hahttp://www.ohsu.edu/son/news/discovery03_4_7.pdf

[186] Cardy P. "Macmillan Cancer relief responds" *Int J of Palliative Nursing* 2004: **10 (5)**; 252.

[187] http://www.hospice-spc-council.org. uk/publicat.ons/text/euthanas.htm

[188] Oregon Department of Human Services (OHS), Office of Disease Prevention and Epidemiology, *Sixth Annual Report on Oregon's Death with Dignity Act.* (2004)

[189] Ganzini, L, and Back, AL, "From the USA: Understanding requests for physician-assisted death". *Palliative Medicine* 2003(a); **17**: 113–4.

6. Assisted Dying Legislation Can Help to Improve End of Life Care

Another argument against legislating for assisted dying concerns fears that this will take away from the provision of good quality end of life care. However all available evidence from Oregon and the Netherlands suggests the opposite. Palliative care in the Netherlands continues to improve and is of a high quality.[190] It has been reported that when assisted dying legislation came into force in Oregon, it served as a "wake up" call to medicine and fuelled progress in improving the quality of end of life care.[191]

Oregon is a leading state in palliative care and this care has improved since legislation.[192] In Oregon, all patients who receive assistance to die are in receipt of hospice/palliative care or have rejected or left this care.[193] The UK Bill also ensures that any patient who requests assistance to die receives access to palliative care.

7. End of Life Treatment Options are Ethically Complex and Not Necessarily Better or Worse Than Assisted Dying

Many healthcare professionals who oppose assisted dying view end of life care options such as "double effect", withholding and withdrawing of treatment and "terminal sedation" as ethically superior and acceptable practice. Yet, as we know, the reality of the situation is often far more complex and unclear. The complexity of end of life decision making was recently highlighted in a European study that explored end of life medical practices in ICUs. The authors concluded that:

> "*The distinction between therapies intended to relieve pain and suffering and those intended to shorten the dying process or hasten death may not be so clear or easily determined. Differentiation may be difficult as intentions are subjective and private.*"[194]

The palliative care option of terminal sedation is increasingly being championed as an effective alternative to assisted dying when faced with a patient who has intractable symptoms and intolerable suffering.[195] However not all patients want to be sedated until death.[196] Terminal sedation is also an ethically complex practice, particularly when accompanied with the active withdrawal of artificial nutrition and hydration.[197] Further and in complete contrast to assisted dying legislation, within the practice of terminal sedation, the patient does not need to be either competent or the decision maker. The practice of terminal sedation also occurs with no national protocols or guidelines and thus, little is known about its actual practice.[198] As a result, it is much more likely that abuse of vulnerable patients will occur as a result of terminal sedation than because of assisted dying legislation.[199]

Conclusion

The vast majority of UK nurses support assisted dying for the terminally ill. Assisted dying legislation, as highlighted by evidence from Oregon and the Netherlands, works well. Where assisted dying is prohibited, it still occurs—often with no regard for safeguards, guidelines or support for nurses who feel compelled to help their patients. Legislation improves communication and trust within healthcare and helps ensure end of life care continues to improve. The safeguards provided in the UK Bill are extremely stringent and serve to protect vulnerable populations far more than under the current legal framework. The pain relief and palliative care filter guarantee that all patients who request assistance to die have access to care options and treatments that may mean patients' needs can be met in alternative ways.

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[190] Korte-Verhoef, R, "Developments in palliative care services in the Netherlands", *European Journal of Palliative Care* 2004; 11 (1): 34–37 and Kuin, A, Courtens, M, Deliens, L *et al*, "Palliative Care Consultation in the Netherlands: A Nationwide Evaluation Study", *Journal of Pain and Symptom Management* 2004; **27 (1)**: 53–60.

[191] Lee, MA and Tolle, SW, "Oregon's assisted suicide vote—the silver lining", *Annals of Internal Medicine* 1996; **124 (2)**: 267–269.

[192] Goy, ER, Jackson, A, Harvath, TA, Miller, LL, Delorit, MA, and Ganzini, L, "Oregon hospice nurses and social workers' assessment of physician progress in palliative care over the past 5 years", *Palliative and Supportive Care* 2003; **1**: 215–219 and Ganzini, L, Nelson, HD, Schmidt, TA, Kraemer, DF, Delorit, MA, and Lee, MA, "Physician's experiences with the Oregon death with dignity act", *NEJM* 2000; **342**: 557–63.

[193] ODHS 2004 *ibid.*

[194] Sprung C, Cohen S, Sjokvist P, baras M *at al* "End of life practices in European intensive care units" *JAMA* 2003: **290 (6)**; 790–797.

[195] Radbruch, L, "Reflections on the use of sedation in terminal care", *European Journal of Palliative Care* 2002; **9 (6)**: 237–8.

[196] Meulenbergs, T, and Schotsmans, P, "Law-making, ethics and hastiness: The debate on euthanasia in Belgium", *Ethical Perspectives* 2002; **9 (2–3)**: 86–96. and Quill, TE, Coombs Lee, B, Nunn, S, "Palliative Treatments of Last Resort : Choosing the Least Harmful Alternative", *Annals of Internal Medicine* 2000; **132 (6)**: 488–493.

[197] Quill, TE and Byock, IR, "Responding to Intractable Terminal Suffering: The role of terminal sedation and voluntary refusal of food and fluids", *Annals of Internal Medicine* 2000; **132 (5)**: 408–422.

[198] Quill, TE, Coombs Lee, B, Nunn, S *ibid.*

[199] Brock, DW, "Misconceived sources of opposition to physician-assisted suicide", *Psychology, Public Policy and Law* 2000; **6 (2)**: 305–313.

For some terminally ill patients, alleviation of their suffering and a dignified end will best be met via an assisted death. Legislation combined with safeguards such as those found in the UK Assisted Dying for the Terminally Ill Bill enables such patients to receive their dignified end. It is essential that as the healthcare group that spends the most time with our patients, we have the humanity, the compassion, and the courage to help ensure that dying people can have this final, dignified, choice.

2 September 2004

Memorandum by Professor John Saunders

The Bill is ostensibly an extension of individual freedom in an area where there are still great anxieties: the manner of our dying concerns us all. It is also well known that the process of dying is the source of distress, pain, anguish and existential suffering for many people. The Bill seeks to address this by assisting those with a terminal illness to have their lives actively terminated. It is my contention that the proposal, while humane in its intention, is unnecessary and will result, on balance, in serious and irreversible harms.

My credibility in making these assertions rests upon a lengthy career at the sharp end of acute general medicine, caring for a very broad spectrum of patients admitted acutely to hospital. I have been almost continuously engaged in this since graduating in 1968, for most of this time on a one in three on call basis; and as a consultant in a district general hospital since 1981. I have probably been involved in the deaths of 1,000–3,000 patients in that time, all causes, all ages. I have also reflected on these issues philosophically and, as a result of my interest in the ethics and philosophy of medicine, hold an honorary senior lectureship at Cardiff University (University of Wales College of Medicine) and an honorary professorship in the Centre for Philosophy, Humanities and Law in Health Care, University of Wales Swansea. I am currently hon Secretary to the Committee for Ethical Issues in Medicine, Royal College of Physicians of London, as well as involvement in a range of advisory capacities to national bodies.

My concerns about the Bill are, briefly, as follows:

— Its title is dishonest. Assisting dying is the responsibility of all doctors and other health care professionals involved with dying patients and particularly those in the specialty of palliative care medicine. This Bill is about active killing. At the very least its title should be changed to the Euthanasia and Assisted Suicide Bill. The choice of title suggests weasel words in order confuse a poorly informed section of the public. It confuses assistance in dying with assistance to die.

— The demand for what the Bill offers is actually small. Publicity for Dutch and Belgian legislation will increase demand as for any consumer product. This correlates poorly with need. My views about euthanasia are not known to my patients. Yet of the thousands who I estimate must have died under my care or received a terminal diagnosis, the numbers who have requested euthanasia can be counted on my fingers. I acknowledge that this is partly a reflection that patients do not ask for something that they know to be illegal. Nevertheless, having been "along side" so many patients at life's end, I think it significant that this request has been articulated so rarely.

— Not only is demand small (—and opinion polls are not a reliable guide, for there are good data demonstrating how our views change dramatically when placed in the real situation: see, for example, the study of quadriparetic patients from Liverpool—), but need is small also. The indication for killing the already terminally ill is suggested as unbearable suffering. While palliative care sometimes fails in its objectives, this is usually due to bad palliative care, not to untreatable suffering. Uncontrollable pain, for example, is rare. The case of Dr Cox and Lilian Boyes, for example, has been quoted as an example of this; but, as was noted at Cox's trial, the assistance of specialists in palliative care medicine or pain control had never been made. Imperfect palliative care indicates the need for better education of health care professionals, not killing the patient.

— The existential suffering and terminal distress experienced by some patients is not something that can be addressed within the time scale proposed in the Bill. Trust takes time to establish. A peaceful and fulfilled end is better achieved by the overt expression and resolution of deep personal conflicts. The terminal phase of an illness may offer a special part of life of inestimable value, as so many patients have testified—*unexpectedly*.

— Covert euthanasia will not be reduced by the Bill. The practice is likely to extend to cases not currently covered as active killing becomes accepted. This has already been seen and documented in the Netherlands. Definitions of "terminally ill" can be stretched (is a patient with anorexia nervosa terminally ill?), freedom from external pressure can be reconsidered and so on.

— Baroness O'Neill has pointed out that the Kantian understanding of autonomy is misinterpreted to mean the licence for an individual to do as he pleases. In reality, autonomy is always limited by the social nature of human life. We have obligations, whether we want them or not. Ownership (—in this case of my life—) does not logically lead to the moral freedom to destroy it when I like. Suicide may have been decriminalised out of recognition that criminal sanction is not an effective way to discourage suicidal conduct. The 1961 legislation "in no way lessens, nor should it lessen the respect for the sanctity of human life which we all share", to quote the minister in the Commons at the time. As an illustration of the principle, we do not find it morally acceptable for an owner to destroy a major work of art, even if his legal right to do so is unquestioned. Most of us disapproved when Mrs Churchill destroyed Sutherland's portrait of her husband. This Bill threatens the traditional prohibition of intentional killing. We will all suffer if this is breached.

— The social ethos of Western society with its strong insistence on the value of human life, even when severely disabled, is likely to be eroded by the Bill. It is easy to stoke up demand for reform by opinion poll: most people supported going to war in 1914, for example. The effects of unwise change may take a long time, but will be difficult, if not impossible to reverse. The social ethos should not be taken for granted. Our freedoms and respect for life are still not shared by many, perhaps most, people in the world. A change in ethos may encourage particular cultural groups to regard themselves even more as a "nuisance" and opt for euthanasia to relieve other family members. A human life has an objective value that morally constrains autonomy.

— The Bill is illogical in its time limits. If the basis for euthanasia is the (freely expressed) wish of the patient, there is no logical reason to limit this to the terminally ill. Why draw a line here? The Bill's proponents should either acknowledge that a simplified view of autonomy is not the moral basis for the Bill; or be honest enough to extend the Bill to those who are not ill at all. The only reason for limiting it to those who are terminally ill seems to be that in the event of error, the loss of life (measured in time rather than quality) is smaller. If on the other hand the moral justification is the reduction of the sum total of human suffering, then the moral basis is flawed by all the problems of utilitarian calculus.

— A lengthy experience has taught me that prognosticating in the terminally ill is fraught with difficulty. I am frequently wrong. The intervals in this Bill are far too long for accurate prognostication in many, perhaps most, cases. The result can easily be legislation that robs individuals of a significant part of the final part of their lives.

— The Abortion Act has changed the attitude of doctors towards abortion (whether for the better or worse is not my point). This Bill if enacted will change the attitude of doctors towards the terminally ill and erode the traditional view of the sanctity of life to a view of life as essentially instrumental ie not something valuable in itself, but only valuable for what one can do with it. I do not believe this will be a healthy change.

— There is no reason why active killing should be the role of doctors. This point is addressed in the submission from the Royal College of Physicians. Skills to kill are easy to teach and like many practical procedures could be delegated to another. I don't lose attachment to, or solidarity with, my patient because I ask a surgeon to replace his heart valve or a physiotherapist to assist his mobility after stroke. The Bill is entirely silent on the reason for involving doctors in this activity.

— Finally, I would wish to emphasise the tremendous vulnerability of the terminally ill. The pressure to do the right thing at the end of life may be enormous for many patients. What could be more "right" than relieving the burdens of others—especially if they appear reluctant to carry them. The changing ethos resulting with this Bill could lead to grave social evils. I am sure that none of the protagonists in the debate over this Bill are casual or indifferent to human misery and suffering. But the case has not been made that intentionally killing people is a better or more dignified solution than relief of suffering by means where death may be a predictable, but not intended, consequence.

Memorandum by Dr Richard Scheffer

Dr Richard Scheffer has been a consultant in Palliative Medicine and medical director of an independent hospice for 16 years. He read, and then taught, social work at the University of Natal, Durban, South Africa in the 1970s before reading medicine at the University of Cape Town. He trained in Clinical Oncology at King Edward VIII Hospital, Durban, South Africa, and Velindre Hospital, Cardiff before going to St Christopher's

Hospice in London to pursue a career in Palliative Medicine. He is involved in both undergraduate and post-graduate education, is chairman of the local Palliative Care Network and is a member of the National Council for Hospices and Specialist Palliative Care.

This evidence is submitted in his personal capacity and does not necessarily reflect the views of his employer or any of the committees on which he serves.

1. KEY RECOMMENDATIONS:

1.1 Assisted dying/euthanasia should be a legal option to those terminally ill patients in the United Kingdom who wish to chose such an option (but this should not detract from the need to offer all patients facing life threatening illness a high quality palliative care service).

1.2 Assisted dying/euthanasia should be limited to individuals suffering from a life-threatening disease which is beyond cure.

1.3 The mechanism by which assisted dying is achieved should be by the establishment of independent "assistants" to prescribe and/or administer the necessary drugs. The *medical and nursing professions* should be *specifically excluded* from the process (beyond the confirmation of diagnosis and prognosis, the exclusion of depression and the discussion of the options of care).

1.4 The Bill in its current form should therefore be *rejected.*

2. INTRODUCTION

2.1 In considering the issue of assisted dying or euthanasia there are three questions that our society needs to address collectively:

1. Do we want to alter the legal code to allow individuals to choose to be assisted to die?
2. If so, in what circumstances should an individual be able to choose this option?
3. What mechanism should be put in place to effect their decision?

2.2 This is a personal paper. My view on euthanasia has changed over the years from being implacably opposed to wanting to find a way to introduce it for the few without compromising the care we offer for the majority. My thoughts are obviously influenced by my clinical experience of 25 years in medicine, most of which have been in oncology and palliative care. But there are other influences too:

— I trained as a social worker, before I read medicine.

— I have a Christian faith.

— I was born and brought up in South Africa during the apartheid years. I saw there how the legal process could be warped to manipulate individuals and society. I am concerned that this should not be possible in well meaning changes to the law over this issue.

2.3 *Definitions:* Much has been written about the question of euthanasia/assisted dying. It provokes strong reactions from both those who advocate it and those who oppose it. Misunderstanding in these circumstances is common. To try to prevent this the following definitions will be used:

"Euthanasia/assisted dying" is the act of deliberately/actively ending the life of an individual at their stated request. (The phrase "assisted dying" will be used in this paper.)

"The individual" is the person requesting/experiencing euthanasia or assisted dying.

"The Assistant" is the person providing/administering the drugs to the individual to assist them to die. (This is a new proposal.)

3. DO WE, AS A SOCIETY, WANT TO ALTER THE LEGAL CODE TO ALLOW INDIVIDUALS TO CHOOSE TO BE ASSISTED TO DIE?

3.1 There can only be a "yes" or "no" answer to this question.

I do not propose in this paper to rehearse the arguments for and against assisted dying in detail.

Those who argue "yes" point to:

— individual autonomy.

— the need to be humane in the prevention and alleviation of human suffering.

— other options, for example palliative care, cannot alleviate all suffering.

— some people, however small their number may be, want to have control over this part of their life.

Those who argue "no" do so because:

— they see each human life as special (the "sanctity of life" argument).

— they express concern that vulnerable members of society will feel pressurised into accepting assisted dying to reduce costs/concern to their family.

— it is not possible to alleviate all suffering in society.

— other options, for example palliative care, can alleviate suffering and improve quality of life.

3.2 I have come to believe that the option of assisted dying should be available to those who want it. I have changed my opinion on this because over the years I have cared for a small number of people for whom this would have been the only humane option. The situations in which I would have felt it right to allow a patient to be assisted in their dying have always been related to the indignity and frustration of the experience of the illness from which they suffered. They have not necessarily had physical suffering, in the sense of their having unacceptable pain or other symptoms, although the disease had altered their physical being eg in making them weak, or unable to speak, or incontinent, etc.

3.3 When, as a doctor, I face a patient with intolerable physical suffering, which cannot be controlled without their being sedated, I can, and do, offer to increase their analgesia and/or tranquillisers, if that is their wish, even if that sedates them, so that they are no longer aware of their suffering. This treatment option is more difficult to justify and apply to someone who is frustrated by advancing frailty and indignity. I am concerned that to extend this treatment possibility to such patients would result in more abuse than would a formal change in the law to allow assisted dying in specific circumstances.

3.4 There is no reason to link the decision of an individual asking for assisted dying to their experiencing "unbearable suffering". The latter is a subjective and indefinable term and using it further complicates an already complicated situation. An individual making a personal choice to ask for assisted dying should be the only criterion necessary.

3.5 The number of individuals in our society, who wish to have the control over this part of their lives, is difficult to ascertain. The experience of palliative care physicians is twofold. Firstly, that a remarkably small number of patients actively ask for assisted dying. And, secondly, the vast majority of those who do ask, usually do so in the context of unrelieved suffering that, once relieved, alleviates their desire to die. The counter argument to this is that it is possible that patients do not raise the issue of assisted dying with palliative care physicians as this is not seen to be acceptable. From other countries, however, and from our experience in the United Kingdom mainly with cancer sufferers, it seems unlikely that the number requesting assisted dying would exceed 5 per cent of persons facing life-threatening disease.

3.6 While accepting that I do not wish to deny this 5 per cent of patients their right to choose assisted dying it is important not to lose sight of the rights and needs of the other 95 per cent of the population. It is essential to continue to offer, and improve where possible, a high quality palliative care service. In changing my opinion to accepting the need for assisted dying I remain concerned about two issues:

(a) how to prevent the relationship of trust between doctor and patient (especially in the 95 per cent) from being damaged by this change in society.

(b) how to prevent vulnerable individuals feeling pressurised into feeling they must choose this option.

(These issues are addressed below.)

4. Under What Circumstances Should an Individual be Allowed to Choose the Option of assisted Dying?

4.1 There are four groups of individuals who may wish to explore an option of assisted dying. These are:

(i) those facing a life-threatening illness with a relatively short prognosis. Examples would be cancer or motor neurone disease.

(ii) those facing a life threatening illness which might/is likely to limit their life expectancy but not necessarily in the short term, but which they perceive limits their quality of life. Examples would be:

— those suffering slowly progressive, neuro-degenerative conditions, eg multiple sclerosis, Parkinson's disease, Alzheimer's disease;

— those with other end stage disease, eg cardiac or lung failure, advancing peripheral vascular disease.

(iii) those facing severe disability, either congenital or acquired, which may or may not limit their life expectancy, but which they perceive limits their quality of life. Examples would be:

— those with severe congenital physical disability;

— victims of severe accidents, eg spinal injuries, burns, etc.

(iv) the fourth group would be all persons who do not fit into one of the above three groups but who consider their quality of life, for any other reason, unacceptable.

4.2 If the concept of autonomy is going to be expanded to include the right to choose assisted dying, then it is logical, ethically, that all four of these groups of individuals should be offered this option. However, it is important to recognise that there is opposition to assisted dying for disabled persons amongst disability rights groups and it is unlikely that our society would wish to give the assisted dying option to anybody who simply fell into group (iv). It is likely therefore, that if we as a society decide to agree to assisted dying, we will want to limit this option to group (i) above, namely those who are facing a life threatening condition with a relatively short prognosis, and possibly group (ii). It should be recognised, however, that there may be problems in defining the limits of group (ii).

4.3 There are two important issues, however, that must be considered whatever the definition of the patient group.

(i) it is essential that depression be excluded. It would be unacceptable to act on requests for assisted death from people suffering from depression, when such requests would be changed by treatment of the depression.

(ii) it is also important that we as a society recognise that many in our society feel very vulnerable, especially when ill, and it is important not to create a situation where the "right to die" becomes a "duty to die" to prevent cost or concern to relatives. It is difficult to see how this can be completely overcome. The only safeguards would be making sure:

— that an adequate quality palliative care service is available to all, and

— that all care options are explicit and therefore able to be openly and honestly considered. (cf para 3.6 b).

5. By what Mechanism Should Assisted Dying be Achieved?

5.1 This is the question that is of particular interest and concern for me. I would argue that it is essential to make the medical and nursing professions independent of the actual administration of the medication used in the assisted dying process. If doctors and nurses are the agents of assisted dying this will radically change the relationship of trust with many of the 95 per cent of patients who do not wish to be assisted to die. (cf para 3.6 a)

5.2 Palliative care physicians already meet many patients who are reluctant to be admitted to a hospice for fear that they will not be given adequate care and just allowed to die or, even worse, have their demise hastened. Many of the 95 per cent of patients who would not request assisted dying would be very frightened by the idea that this may be done to them without their request. Although a change in the law would not legally change the status of an individual not choosing assisted dying it is likely that the change in the law will make many in the 95 per cent group more frightened of the medical profession. It is essential the relationship of trust between doctor and patient is not eroded.

5.3 If we accept that assisted dying should be possible then this should be achieved by the creation of a specific role in our society of "the assistant" in assisted dying who would be a technically trained person able to prescribe and administer the necessary drugs.

5.4 There are two possibilities:

(i) the provision of medication taken orally by the individual, at a time, and in a setting of their choosing (this may or may not be in the presence of the Assistant); and

(ii) the administration, by the assistant, of an injection, either directly into a vein or under the skin, that will sedate and then cause a cessation in breathing and consequently death.

5.5 Each of these options has advantages and disadvantages and it is likely that both should be offered to all individuals requesting assisted dying.

(i) the provision of oral medication to be taken by the individual at a time of their choosing has the obvious advantage of giving the control and the timing of the act entirely to the individual. The major disadvantage, however, is that oral drugs may be poorly absorbed. Consequently doses needed to bring death will vary and death may not be instant, which may cause added stress to relatives or, indeed, the individual, should they recover consciousness; and

(ii) the administration of an injection by an assistant has the advantage that death is assured and instant but the disadvantage is that the individual and Assistant must be brought together. This will involve some planning and loss of control on the part of the individual.

6. A Possible Process

6.1 A possible process for assisted dying would be:

1. The individual expresses a wish for assisted dying to their usual medical carer and confirms this in writing by completion of a specific form.

2. The diagnosis and likely prognosis are confirmed by the consultant under whose care the diagnosis and treatment of the disease have occurred.

3. The options for care are discussed with the individual by a palliative care physician or specialist nurse. This would be to specifically discuss the palliative care option or to consider assisted dying. This may not be achieved in one meeting.

4. A diagnosis of clinical depression is specifically excluded by a psychiatrist.

5. The family of the individual are involved in the discussions.

6. The individual (and their family) is referred to the assisted dying clinic where the assistant will explain to the individual the options of:

   (a) having oral medication made available to them to use at a time and place of their choice; or

   (b) having an injection, at a time of their choice, administered by the assistant.

7. There is a "cooling off" period.

8. The person is assisted to die.

6.2 It is recognised that there are many practical issues that would need clarification in such a pathway. It is included here to facilitate understanding of how a system using assistants and assisted dying clinics could operate.

7. Summary

We should as a society:

- accept that some people will want to control the timing and mechanism of their death and legislate accordingly;
- explore the ways of defining the limits of the group to whom this option should be available;
- exclude the medical and nursing professionals from the actual process of assisting dying as their involvement risks compromising the relationship of trust between professional and patient;
- create the mechanism by which people can be assisted to die if that is their choice;
- reject the Bill in its current form but ask the Select Committee to advise on how this matter can be taken forward with suitable safeguards; and
- recognise that no change in the law will solve all problems and in fact changes in the law will bring new challenges, to individuals, the professions and to organisations such as hospices.

August 2004

Letter from A D Wade, MA

The radical importance of what is at issue in the above bill, the absoluteness or otherwise of the right to life, requires any in-depth submission to it, to take a stand on one side or the other. May I therefore ask you to be ready to give your careful attention to the reasoning behind the following points the uncompromising tone of some of which could otherwise make them appear a little simplistic.

The submission I wish to make can in fact be summed up as saying that the life of any human being amounts to his or her very personality itself and that any requirement of the discontinuance of a person's life will therefore entail the evaluation of that very person him or herself as of lower priority than whatever the consideration is on whose strength his or her life is judged worth discontinuing. Even if such a consideration were to be that person's own choice, it would make no difference, since his or her choice would be either reasoned, in which case it would be based on a consideration in comparison to which others besides that person could equally judge his or her life to be of lower priority, (ie if any such consideration justified seeking to end a person's life, its justification could be seen just as plainly by other people besides the person whose end is being sought); or else that choice would be unreasoned or even arbitrary, in which case, if that person's life is to be thought to have any value at all, such a choice could or should be altogether overruled as unjustified. However, if a person just is his or her own life then each one of us is "all we've got" and if ever one has not

the right to be who one is, or to be at all, then one can certainly, at least at some point of one's existence, have no other rights either.

If this point is accepted, then the above bill has to be seen as totally misconceived from the start. Dying, whatever else it is, is a process of irreversible destruction of a living organism, and human death is the total and irreversible destruction of a human organism. Failure to take this fact into proper account, I would suggest, is a result of mixing up the essential nature of death with circumstances which can effect, but are incidental to it.

The removal of sensation and therefore of suffering that can accompany death, is essential to anaesthesia, but not essential to death itself, which can also incidentally be painful.

Being an essentially irreversible organic destruction, death as such can bring no benefit to whatever undergoes it. Whatever benefit it may bring about incidentally, like the cessation of pain, can at least in principle be brought about by other means, especially in the course of palliative care. It may incidentally be true that a dead organism does not feel any pain, but it is essentially true that a dead organism does not benefit from not feeling any pain, since it is not there to do so. Non-existence is no benefit at all. It is essentially no freedom from pain, or from anything else, since it is nothing and is no one who can benefit or be free or anything whatever. By contrast, while there's life, there's hope, and to kill someone is to kill all hope for him or her. It involves inevitably the judgement that a person's life is worth no more than what it is contemplated killing him or her for. "To be or not to be" is very much a question for human beings. Animals know what they like about life and what they do not like about death, but they do not know what life and death are. As far as an animal is concerned, there is no essential difference between life and death, since it knows only what is incidental to either. Accordingly, an animal which is no longer able to enjoy life, would not be capable of knowing what it is losing if it were destroyed, whereas a human being would.

It is for this reason, I would maintain, that there is no human priority possible that could ever justify deliberately seeking anyone's death, that is, except for the protection of the lives of other innocent human beings from unjust threats to them (and then only as a very last resort—The immense difficulty in the past, of finding effective practical alternatives to capital punishment for incidentally securing public safety, would have obscured its essential unsuitability as a means even of doing that).

The idea, therefore, behind an "Assisted Dying for the Terminally Ill" bill, namely, that "dying" is something that can be "assisted" is as absurd as would be the idea of "assistance" to taking up drug addiction or to getting ill. The idea, furthermore, that there is such a thing as a "right to die", in the light of the above, is just grotesque. There is a human right, of course, to be as free as can be managed from suffering, but to seek to use death as a means to fulfilling it, is the most destructive form of the "use of a sledgehammer to crack a nut" as could possibly be contemplated. Those who advocate the deliberate procurement of a person's death to free him or her from suffering, would seem to me to have confused death itself with an outcome which is incidental to it, and to which death itself is incidental.

It is a confusion that does, therefore, not necessarily feature in the decision to accept death as an unavoidable, but nevertheless still incidental, outcome of procedures essentially of painkilling. What might justify accepting a person's death as an unwanted by-product of easing his/her serious suffering, would not necessarily involve, and would not justify, wanting that person dead for whatever reason, or justify deliberately seeking that person's death as someone whose life is now not worth living, whose very right to exist is now or at any time purely incidental to something else that is not him or herself, like for example, being out of pain, or the preserving of scarce and expensive medical resources, or even to that person's own choice.

It is a very common error, but in my view still an error, to suppose that killing someone is morally right if that person wants to be killed, and so long as he or she wants to be killed by the person or persons who are faced with the decision to do it. It incorporates the judgement that the continued existence of the person concerned is incidental to his or her wanting to exist. More fundamentally, it suggests that the rightness of any course of action is relative to the choice of it, rather than the rightness of the choice relative to the rightness of the action chosen. Yet, if it were the freedom of its choice that made an action right rather than wrong, there would be no such thing as a wrong or unwise choice. Such a principle would also make nonsense of the present bill as currently entitled, because it advocates "assisted dying" or "help in killing" of "the terminally ill", whereas "being terminally ill" would be a self-defeating restriction on any bill that assigns the supreme level of priority in deciding whether a person is to live or die, to personal choice of the person concerned. In that case all such a bill could reasonably require is that the person concerned would have decided not to tolerate his or her situation anymore, thereby rendering his or her situation "intolerable" by definition, whether that person were "terminally ill" or not.

Any interpretation of this bill, however, under which it does not enshrine a person's own decision as the decisive factor in whether or not to seek his or her death; (for example, if it is accepted that a purely arbitrary decision is not a decision at all but an accidental result of uncontrolled impulse or depressive illness,) would

in fact entail accepting that such choice itself would require justification. Any provision of the bill, therefore, for adequately ensuring that anyone who opts for "assisted suicide" is of sound mind, is in fact an acceptance that there is very much such a thing as unwise and unreasonable choice determined objectively by the nature and/or the consequences of the actions chosen, and subjectively only by what the chooser knows or ought to know about the nature and consequences of his or her choice. Whatever, therefore, would justify a person choosing to die would also essentially justify another person or persons to seek to take that person's life with or without his or her consent. It would, of course, be more considerate and indeed respectful on the part of the medical or juridical authorities, if they left the person concerned to choose whether to have him or herself killed, but only incidentally, that is, other things being equal; just as it would be regarded, other things being equal, as only incidentally considerate and respectful to parents, for example, on the part of the civic or public authorities to allow them to control the behaviour of their own children without interference. However, if parents were to be judged incapable or unwilling to properly exercise their right of control over their children, few would be in any doubt that public bodies, like the social services, might properly judge it their duty to step in and do the job for them. In the same way, whatever the circumstance that would ever be serious enough to justify the choice to take a human life, it could thereby equally justify, other things being equal, doing so incidentally without that person's consent, in the event of him or her being unable or unwilling to give the relevent consent properly required in that circumstance by the appropriate authorities, for what would be a fully and seriously justified course of action. A person's choice in the one, as in the other matter would be, howsoever incidentally desirable and worthy of consideration, still equally neither essential nor inalienable to the person or persons concerned if the right of whose exercise it is the choice, is itself not inalienable; and no right is essential or inalienable, if anything could ever justify a decision to alienate it.

To attempt to treat the right of choice in that circumstance as essential or inalienable, by legislation, would be rightly seen as a thoroughly artificial device lacking any logic or moral basis, and simply a disproportionate attempt at pandering to groundless and imagined fears that real people may in fact never have. The resulting legislation would be be inept and crying out to be honoured only in the breach; as I understand is now actually happening in the Netherlands, where in spite of legislation to protect a person's right of choice over his or her own death, only a little over half of all cases of euthanasia are even reported to the relevant authorities at all, let alone carefully screened beforehand.

Even though one's life is initiated without any choice on one's own part in the matter, unlike a game, which one can choose to be in or out of at the start, there is every reason to choose to go along and continue with it. The right to life is essential to any other right that one could ever have, simply because no other right can be more important to anyone than the person him or herself that stands to benefit from it. A person, then, is his or her own most important right.

Conversely, even though one is free to choose to end one's life, there is essentially no point in having oneself killed. If it is accepted that death just is one's breakdown irreversibly as an organism into one's component chemicals, then one would no longer be there to benefit from dying. Only if one were oneself worth nothing as the person one is, would there be any point even incidentally in choosing to die. Whatever incidental benefit appears to accrue from a decision to self-destruct, is actually swallowed up in the essential self-hatred of wanting one's own annihilation. It even smacks of "cutting off one's nose to spite one's face", and is rendered essentially unnecessary by the availability, at least in principle, of less destructive means of attaining any benefit. Like a game, life embodies rules; unlike a game its first and foremost rule is that there is no point at all, only shame, in not playing. The temptation of their supporters to endow people determined to put an end to their lives, with an aura of "dignity" in dying at a moment of their own choosing, instead of waiting for death to "happen to them", I think, is really creating an illusion to mask an essential petulance in the choice no longer to choose, which is self-revoking, and therefore invalid. The idea that their choice to self-destruct is an achievement of mastery over their own destiny, is again, I think, to confuse mastery with power simply to destroy, and no more impressive than the exercise of mastery over a beetle by stamping on it.

As in most card games, one has "to play the hand one is dealt", and one can only ever "throw in one's hand" if and when the rules of the game allow it. The rule of life is to live. Dying can only be considered as "part of life" in the same sense as losing is part of a game. Just as losing may become inevitable in a game, it is never the rule in a game to seek to lose; and any player who opts out altogether because he or she is losing, is rightly thought not to be acting in the proper spirit. Any player who seeks to lose, undermines the game's very point. Opting out of life by choosing to end it, would seem, then, as alien to the proper spirit in which to live, as to opt out of a game would be, by seeking to abandon or lose that. It would be literally "not playing the game".

To maintain, in opposition to the above, that anyone's life can ever not be worth living, must, therefore, be the presupposition behind this bill. Indeed the standpoint of my whole submission might well be felt by this bill's supporters to be highly unfeeling or uncaring, by comparison to theirs, and attract the *argumentum ad hominem* that runs, "It's alright for you to talk, when it is not you who are suffering from Parkinsons,

Alzheimers, Korsakovs or Motor Neurone, or other kindred diseases; it is easy for you to go on bleating about "Play up! Play up! And Play the game!", but just wait until you are suffering like that, and then let us see whether you don't start singing a very different tune." This argument invites the answer, though, that, be that as it may, it still would not help me or anyone else in circumstances so frightful as to remove all intermediate options between heroism and despair, to encourage sufferers to believe that "the game is not worth playing", with the inevitable insinuation that, if we are suffering any one of those dreadful conditions, we count for nothing anymore, which would be an infamous and psychologically debilitating lie.

Only if people are no better than their circumstances or are worth only as much as their health, would life be not worth living without these assets. But then, personal value would amount only to quality of life, and if health and prosperity would be the point of human life rather than human life the point of health and prosperity; human beings would become essentially defined, shaped and even controlled by their circumstances and would only incidentally define, shape or control those circumstances. If the players of a game were essentially manipulated by the equipment and environment of the game, instead of being incidentally conditioned by them, there would be no essential difference between them as organic beings and the venue and equipment as their inorganic tools. If, therefore, life could be legitimately abandoned, and if there were no "proper spirit in which to approach life", at all, there would indeed be "no game to play" as such, as all "moves" in it would be essentially the automatic movements proper to its non-living "kit" and environmental conditions. Human life would be simply one effect among others of lifeless forces, and there would be no essential difference between human life and its non-living environment, all observable differences being merely incidental; which the framers of this bill perhaps think is in fact the case.

It is certainly a necessary presupposition of the bill, the very idea of whose provision for legalising the killing of human beings, rests on destroying any essential distinction between human life and its inorganically material environment. It is a bill which, if passed, will subtly teach the nation that human beings are different forms of matter only incidentally from non-living, let alone non-human, forms, and the contrast between humanity and inhumanity will have been eroded away in favour of "non-humanity", as being scientifically more appropriately value-neutral in a situation in which "sub-human life" and lifelessness itself are as much standards of humanity, as humanity would be of them. A more potent undermining of people's appreciation of the value of human beings and the rights and responsibilities that stem from it, can hardly be imagined, than this bill, finally justified, as it must be, only on the premise of a reduction of life essentially to the status of things that are without it, May I suggest then, that any attempt to re-educate people, very many of whose understanding of human rights is based on considerations of principle entirely alien to those underlying such a bill, means of having this bill passed, would be perniciously underhand, legally oppressive of the consciences of its opponents, particularly in the medical profession, and morally and culturally corrosive.

I must, therefore, urge its withdrawal in the strongest possible terms.

1 September 2004

Memorandum by Dr Ian R Williams

1. General Background

1.1 My comments refer to this situation only. While I am aware of very significant arguments advanced by some groups for the legalisation of euthanasia, those are not within my sphere of competence.

1.2 I do not claim any particular expertise or knowledge of the ethics of medical practice nor of the minutiae of palliative care. I have, however, been a consultant neurologist for some 27 years having a particular interest in people affected by chronic neurological conditions and the services and resources available to help them. The specialty of Neurology includes the diagnosis and care of people with conditions such as Motor Neurone Disease, Multiple Sclerosis, Parkinson's Disease, Huntington's Disease, Muscular Dystrophy, the ataxias and a wide variety of less common, chronic and incurable diagnoses. For more than 10 years I was the Medical Director (or equivalent) in the Walton Centre for Neurology and Neurosurgery in Liverpool. I also provided neurological input to younger disabled units in Liverpool and Carnarfon. For many years I have been an assessor for the provision of electronic "environmental control equipment" to severely disabled people living at home. I was instrumental in setting up the Glaxo Neurological Centre in Liverpool. This Centre, which is unique in the UK and has been open for 10 years, is a charity sector, non medical advice and support centre for people affected by neurological conditions, their family and carers. I have been closely involved with many of the Neurological Charities locally and nationally and have recently been invited to join the Care Development Advisory Team of the Motor Neurone Disease Association. I was a member of the External Reference Group for the National Service Framework on Long Term Conditions appointed by the Minister of Health. Thus I have considerable experience of the situation that forms part of the background to this Bill. I am an active member of the Methodist Church.

1.3 I have read the current Bill, its predecessor, the debates reported in *Hansard* on 6 June 2003 and 10 and 31 March 2004 along with papers prepared by the BMA, the Royal College of Physicians and the Association of Palliative Medicine and National Council for Hospice and Specialist Palliative Care Services.

2. Comments

2.1 A Societal Issue

2.1.1 Issues of life and death are not medical issues.

The enactment of the processes of assisted death necessarily involves health care professionals and entails the use of practical expertise: that does not confer on those professionals any greater responsibility for agreeing the ethical framework within which their actions take place. Indeed there could be dangers in giving undue weight to the viewpoint of the practitioner rather than to the participant. Thus I think it is important not to allow the debate to be dominated by the views of doctors whether members of the House of Lords, the Colleges, the Specialty Groups or individuals except when giving technical medical advice or helping with understanding the nature of some of the conditions and their effects.

2.1.2 The Doctor-Patient Relationship

Opponents of the Bill seem to raise two objections under this heading. One could be loosely described as fundamentally changing the relationship, while the other seems to focus on a loss of trust.

(a) Fundamental change

It could be argued that the doctor-patient relationship should change fundamentally. There have been numerous examples over the past few years to suggest that all is not well. Although the relationship between professionals and their clients has changed considerably over the last 25 years, the transition from omniscient and possibly omnipotent, paternalistic, authoritarian consultant to informed, skilful, accredited and up-to-date advisor, supporter and guide is not yet complete! If we are now discussing the possible consequences of listening to the needs of patients in their distress and together finding ways of addressing those needs, that is very much to be welcomed.

(b) Trust

Some of the opponents have suggested that giving doctors the ability to respond to a patient's repeatedly expressed wishes would undermine trust between doctor and patient. People would fear that the doctor would abuse the relationship and act outside the wishes of the patient. It is hard to see why this should be so given that more than 80 per cent of the population agree that assistance should be available to people wishing to die when life becomes intolerable. It would be odd if a loss of trust were to be the result of acting in the interest of, and at the behest of, a patient in a society where such action is approved. Experience from Holland does not lend any support to this concern either.

(c) Failure

Medical training, at undergraduate and postgraduate levels, and the professional ethic and tradition rightly place a high value on the saving and maintenance of life. Little time is spent on trying to understand the value of life and the moral, ethical and religious framework within which people live their lives. In trying to analyse the reasons why doctors should be so concerned about the possible impact on the doctor patient relationship of a doctor agreeing to a patient's plea for assistance in dying, it might be worth considering the concept of death as failure, and thus as damaging the consultant's image of himself. However, if assisting death in the very limited confines of this Bill, is seen as fulfilling the needs of the patient that should allow a different perspective; just so long as the professional sees that as his/her role. Again a redefinition of the role of the professional might enable assisting death to be seen as enhancing the doctor patient relationship.

2.2 The Dying Process

My experience is of neurological conditions. These are usually chronic lasting many years with slow loss of function, independence and self esteem. This chronicity raises some important issues in the context of the Bill. (Motor neurone disease with a life expectancy of only 1–3 years, on average, from diagnosis is an exception. It is the most rapidly progressive and one of the most unpleasant.)

2.2.1 Dependence

During the years of progression of a chronic neurological condition a very different relationship can develop between patient, carer and doctor. Sometimes there is a dependence inherent in the long term caring process: this can be in both directions. Such a dependent relationship could make it either easier or more difficult for

the patient to raise with the doctor the possibility of assisted death. If the Bill is to proceed it will be necessary to introduce safeguards to prevent this group of vulnerable people from feeling under pressure to ask, or not to ask, for assistance in dying.

One possibility would be to create a separate route for the request for assistance to die. The creation of an advocate or "Patient's Friend" to whom any such request had to be made could also go some way to addressing the concerns of others about the doctor patient relationship, or the unlawful extension of the process to allow involuntary assisted death. The "Patient's Friend" would have to be readily available, independent of the care provider and would have responsibility for initiating the process described in the Bill.

Details of the role and person would be much further down the line if the idea were to be accepted. Not only could such a person be of value to people in a dependent relationship with their consultant and/or GP but if it were made compulsory to start the process through such a person, and not through the consultant/GP delivering care, that could reduce people's fears about involuntary assistance. No process could be started by approaching the doctor. A patient wishing to activate the process would approach the "Patient's Friend" who would then set in train the series of consultations described in the Bill only if the requisite conditions were met. It would be the "Friend's" responsibility to gather the information and opinions needed and to decide with the patient whether the conditions were met. Only then could arrangements be made. The "Patient's Friend" could also be an important part of the monitoring process: it would allow greater confidence that all procedures had been completed and that only people falling within the criteria of the Bill were considered, at a stage before death had been assisted. The Bill currently includes a monitoring of the procedures only after the event.

2.2.2 Palliative care

Currently palliative care facilities are not available to the majority of people with chronic neurological conditions. Outside the diagnosis of Cancer and possibly motor neurone disease, such care is the exception. This is partly due to inadequate capacity and restrictions resulting from dedicated funding, but is also due to a lack of understanding of neurological conditions in the palliative care community and a lack of palliative care awareness in the neurological community. Where palliative care is available and awareness exists, it is likely that it will have been discussed with people as an option during the long duration of the condition.

Strictly speaking, to meet the demands of the Bill, it will only be necessary to provide a palliative care specialist to give an opinion about the potential for the relief of suffering and thus remove the desire for assistance to die. To provide the palliative care that such people might then require, the capacity of palliative care in the UK would have to expand very considerably and new understandings and relationships between palliative care and neurology would have to be formed.

The ability to offer everybody with chronic neurological conditions appropriate, continuing, palliative care before they can consider assisted death might not be a logistical possibility with present resources. In the absence of such care more people are likely to find their suffering unbearable and seek assistance to die.

2.2.3 Terminal illness

Many specialists will have been involved and many options discussed with the patient and carers during the progression of a chronic neurological condition. Thus the recognition that the condition is terminal is in one sense easy and were assisted dying to be allowed that too would presumably have been discussed among the options. It is, however, difficult to know when, in this process, dying begins and hence when a chronic condition becomes a terminal one. This is more than a theoretical question as the Bill applies to terminal illnesses. The definition of "a few months at most" might well not be very helpful in many neurological conditions. People with multiple sclerosis, knowing what is to come, might well want to avoid the years of real suffering that can precede death; people with motor neurone disease might know when they can cope no longer but clinicians might not know with any certainty how long the patient would survive.

It might be possible to avoid that problem if permission to assist death were to depend on the inability of the patient to cope any longer but clearly this creates another set of problems. Perhaps one has to accept that not all people who wish to be assisted to die will meet the very narrow criteria of this Bill even though their suffering, and their wish to die, is as great.

3. Protecting Vulnerable People

The discussion about the issues that are the subject of this Bill recognises that there is a need to protect vulnerable people from pressures to seek assisted death. I have not seen a similar discussion about the equally real need to protect that same group of vulnerable people from the pressure to stay alive in spite of their suffering. It is possible to exert such pressure either through looking at the situation from the professional's ethical standpoint and values rather than with the desire to respond to the patient's needs; or through giving

selected information. People will make their decision about whether to undergo a particular treatment or withdraw from current treatment on the basis of the information available to them.

The way in which information is presented will affect the decision. For example when discussing possible treatment with a person who has Motor Neurone Disease one could say that it is an incurable disease often leading to death within 3-5 years, but sometimes much longer, and that with modern treatment it is possible to treat such symptoms as might arise: death is usually peaceful occurring during sleep. Alternatively one could say that it is a rapidly progressive disease leading to death within about a year for most people. The progression deprives people of one function after another leaving them immobile, dependent, choking and unable to communicate. Quite the most awful disease. It would not be surprising if patients receiving such different information reached different conclusions about their treatment.

I do not believe that dying is something that people find easy. Although Palliative Care can ease the suffering for people, death and dying are still undignified for many: we should not mislead them into making decisions that increase their suffering either by imposing our own code on them or by slanting the information they receive. Protection is not just about the right to life.

SUMMARY

1. The submission is from a neurologist familiar with the predicament of people with chronic, progressive conditions such as Motor Neurone Disease and Multiple Sclerosis.

2. The submission generally supports the concept of assisted death within the tightly defined criteria in the Bill.

3. Recognising the vulnerability of people to pressure to ask for assisted death, or pressure to put up with their suffering, the submission suggests the creation of a "Patient's Friend", independent of the care providers, through whom all requests would be made. This person would have responsibility for ensuring that the tight criteria of the Bill were applied.

4. Issues of doctor-patient relationship, involuntary assisted dying and monitoring are discussed.

5. The submission notes the need to increase the availability of palliative care and to improve the understanding of, and training in, palliative care for neurologists and in the management of long term neurological conditions for palliative care specialists.

August 2004

Letter from Dr Z Zylicz, Comprehensive Cancer Care, Nijmegen, Netherlands

I have read with a great interest in full your Assisted Dying for the Terminally III Bill. As a medical specialist involved for 12 years in palliative care in the Netherlands I would like to comment on your Bill proposal. During past 12 years I spoke to many hundreds of patients willing assisted dying and I consulted thousands other dying patients.[200]; [201] Your Bill is at least similar to the law endorsed by the Dutch Parliament, so my suggestions born out of practice may be relevant for you.

The normal process of dying, let say from the time of breaking bad news and death may be divided in three different stages. At the stage one there is a lot of imbalance, doubt and lack of information. The patient did not accept yet the diagnosis. He or she may experience severe pain and other symptoms, but their treatment may be insufficient in the beginning. As the patient feels hopeless, he or she may consider euthanasia or assisted dying. In the perception of the patient pain and other symptoms may be experienced as overwhelming and unbearable. The disease by itself, or improper pain medication may cloud patient's consciousness and add to his misery and anxiety. The patients, and there are many of them in the Netherlands, may refuse effective measures to force the decision of assisted dying.

Proper information, meticulous personal care, attention to details and knowledge of palliative care are able in nearly all patients refered to the palliative care to achieve the second stage of dying. The stage of equilibrium. When the patient receives adequate treatment the pain and other symptoms may become bearable. The hope may return. The consciousness is usually intact and the patient is able to participate in a process of adaptation to terminal illness. At this stage we see that most of the requests of assisted death are postponed. However, few patients confronted with longer lasting stage two, may renew their requests as they may think that their terminal condition will last for ever.[202]

[200] Janssens RJ, ten Have HA, Zylicz Z. Hospice and euthanasia in The Netherlands: an ethical point of view. *J Med Ethics* 1999;25:408–12.

[201] Zylicz Z, Janssens MJPA. Options in Palliative Care. Dealing with those who want to die., In: Zenz M, editor. Cancer Pain, vol 12. Baillere Clinics of Anaesthesiology; 1998. p 121–31.

Independently of adequate symptom control most diseases like cancer will progress and the stable stage two may progress to instable last stage of dying. This stage is characterised by an unusually high dynamics, new problems arise daily. Symptoms which were adequately controlled until now may appear less controlled now. New symptoms appear. More drugs are used and the consciousness (and competence) of many patients at this stage may be impaired. Some patients at this stage may wish assisted dying, calling upon their earlier declarations, but they may fail to prove competent, while undoubtedly suffering.

Analysing intentions of your Bill, with built-in security of 14 days, I understand that you are addressing patients at stage one of the dying process. My comments to this is as follows:

- Most of these patients, with proper and timely care will eventually withdraw their declarations and will not regret this.
- Some patients will try to avoid contact with professionals in palliative care to "prove" their symptoms are untreatable and suffering unbearable.
- Some patients with slowly or not progressing conditions, may be discriminated by your Bill, as they will be refused assisted dying.
- Practising assisted dying on terminally ill patients which with proper treatment still may improve, seriously impairs learning process of physicians. If all problems in terminally ill would be solved by assisted death, the knowledge how to treat these symptoms may be impaired. Eventually you may be confronted with the fact that physicians who practise euthanasia will not know how to address the problems of their patients.
- your Bill does not address the problems of people suffering in the stage three. The public will not understand why the patient imminently dying and unbearably suffering can not be assisted in his/her dying, while a more competent patient, able to articulate (but also manipulate) his/her suffering will be granted this help.
- In stage three, traditionally, most of problems with unbearable suffering are addressed by increasing the doses of painkilling and/or sedating drugs, even if this would cause sedation and eventual death. This method is ethically accepted and effective in alleviation of suffering. In your Bill there is no difference between sedating imminently dying terminally ill patients and assisted death.
- In your Bill, among qualifying conditions, age of majority is mentioned. You should be aware that this very point will fuel an endless and inconclusive discussion as the age of majority is an artificial cut-off line devoid of any understanding and respect for suffering. You try to solve problems of the responsible majority, increasing suffering and neglect of the others.
- The 14 days waiting period may also be seen as impractical and inhuman. Most of the patients awaiting assisted dying will decrease the doses of the pain killing drugs to avoid incompetence at the end of this period. I find this inhuman as you cause suffering, not even trying to diminish it.
- You are addressing anxiety of some, increasing anxiety of many others.[203]

I hope my points will move you to reconsideration of this Bill. By copying the law from the Dutch you can not avoid twenty years of public discussion which took place in the Netherlands. Endorsement of the law on assisted dying had several very positive effects on Dutch public. It vigorously stimulated development of palliative care. In fact the numbers of patients dying with euthanasia are decreasing. The Dutch law may prove outdated very soon.

1 September 2004

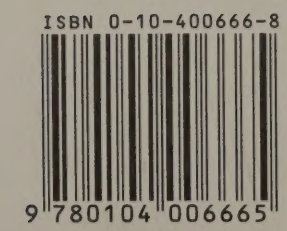
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